

Symptoms and quality of life of women with breast cancer, before, during and after radiotherapy

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Contents

Contents	1
Acknowledgments	3
Publications included in the dissertation	5
Abbreviations	6
1.0 Introduction	7
1.1 Breast cancer – definitions and treatment	8
1.1.1 Stage of disease	8
1.1.2 Treatment	10
1.1.3 Surgery	11
1.1.4 Radiotherapy	11
1.1.5 Chemotherapy	11
1.1.6 Hormonal and antibody therapy	12
1.2 Background	12
1.2.1 Literature Search	12
1.2.1 Symptoms – definitions	13
1.2.2 Symptoms – literature review	14
1.2.3 Quality of life – definitions	16
1.2.4 Quality of life – literature review	17
1.3 Theoretical framework – the Theory of Unpleasant Symptoms	20
2.0 Aims of the study	23
3.0 Methods	24
3.1 Study design	24
3.2 Patient recruitment	24
3.3 Inclusion and exclusion criteria	25
3.4 Data collection and follow-up	25
3.5 Data handling and initial quality assurance	26
3.6 Instruments	26
3.6.1 Demographics	27
3.6.2 Karnofsky Performance Status Scale (KPS)	27
3.6.3 Self-Administered Comorbidity Questionnaire (SCQ – 19)	28
3.6.4 Memorial Symptom Assessment Scale (MSAS)	28
3.6.5 Translating the MSAS into Norwegian	29
3.6.6 Short Form 12 (SF – 12)	30
3.7 Ethical considerations	31
3.8 Statistics	32
3.8.1 Overall considerations	32

3.8.2	Sample size calculation.....	33
3.8.3	Paper I – analyses	33
3.8.4	Paper II – analyses	34
3.8.5	Paper III – analyses	35
4.0	Results	37
4.1	Participants.....	37
4.2	Compliance	39
4.3	Summary of papers – main results.....	41
4.3.1	Paper I.....	41
4.3.2	Paper II.....	42
4.3.3	Paper III.....	43
5.0	Discussion	45
5.1	Methodological discussion	45
5.1.1	Design	45
5.1.2	Patient recruitment, compliance and representativeness.....	46
5.1.3	Psychometric properties of the instruments.....	48
5.1.4	Memorial Symptom Assessment Scale (MSAS).....	50
5.1.5	Short Form 12 (SF – 12)	51
5.1.6	Self-Administered Comorbidity Questionnaire (SCQ – 19)	51
5.1.7	Data analyses.....	52
5.1.8	Theory of Unpleasant Symptoms	52
5.2	Main results.....	54
5.2.1	High symptom burden before radiotherapy	54
5.2.2	Similar pattern for the trajectory of occurrence, severity and distress	55
5.2.3	The importance of chemotherapy on symptoms and quality of life.....	56
5.2.4	Minimal change in quality of life during the course of radiotherapy.....	59
6.0	Main conclusions.....	60
6.1	Implications for clinical practice.....	61
6.2	Future research	61
	Reference list.....	63
	Paper I-III	
	Appendix	

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3. Hofsø, K., Bjordal, K., Diep, L. M., Rustøen, T. The relationship between demographic and clinical characteristics and quality of life during and after radiotherapy: in women with breast cancer. *Quality of Life Research*. 2014; 23(19), 2769-2777.

Abbreviations

ALND	axillary lymph node dissection
BCS	breast conservative surgery
CRF	case report form
CTX	chemotherapy
DCIS	ductal carcinoma in situ
KPS	Karnofsky performance status scale
MCS	mental component score
MSAS	memorial symptom assessment scale
PCS	physical component score
REK	regional etisk komité (regional committee for medical and health research ethics)
RT	radiotherapy
SLNB	sentinel lymph node biopsy
SCQ-19	self-administered comorbidity questionnaire
SF-12	short form 12
SF-36	MOS 36-item short form health survey
TNM	tumor node metastasis
TOUS	theory of unpleasant symptoms
QOL	quality of life

1.0 Introduction

The incidence rate of breast cancer has increased internationally and in Norway since the 1950s (1), and today breast cancer is the most frequent cancer diagnosis among women in Norway, with 2956 women diagnosed with the disease in 2012 (2). The five-year survival rate for women with breast cancer (all stages), increased from 67 % in 1970 to 89 % in 2011 (3). The implication of both higher incidence and survival is that more women are living with the psychological and physiological symptoms that accompany the disease and its treatment.

Women with breast cancer may have both subjective symptoms and objective signs of disease before they often receive multimodal treatment (4-7). Symptoms can be caused both by the illness itself and by treatment. Each treatment carries a risk of causing a set of new treatment-related symptoms (8-13). Symptoms represent a departure from the normal function or feeling (e.g., pain, nausea, or anxiety), are observed by the patient, and can seldom be measured directly. Self-report is therefore most commonly used to register symptoms both in research and clinical situations.

Symptoms frequently reported for women receiving treatment for breast cancer are fatigue (8;14), arm morbidity (9), pain (15), nausea (13;16;17), difficulty sleeping (8;18), cognitive dysfunction (17;19) and depression (8). Recent evidence shows that these women are experiencing multiple symptoms simultaneously (20-22), which decreases the functional status and quality of life (QOL) for the women experiencing it. The evidence on multiple symptoms for this patient group is limited (20-22), despite extensive knowledge on individual symptoms. The symptom burden requires attention because it may affect the women and their families negatively.

As a nurse, I was interested in investigating the symptom experience for women with breast cancer going through radiotherapy (RT), as nurses are typically confronted with symptoms that patients are experiencing through cancer treatment. When women with breast cancer start RT, they have already received one treatment (e.g., surgery) or a combination of treatments (e.g., surgery and chemotherapy (CTX)), which may lead to different symptoms. Additional RT is associated with further symptoms. These women usually receive RT as outpatients. Since these

patients are living at home, without being seen by health care providers every day, it is of great importance for these patients to be aware of the potential symptom burden and the trajectory of the symptoms that they may experience during treatment. Equally important for these patients is knowledge about strategies to help them cope better with the symptoms they experience.

This dissertation examined the symptoms and QOL for 188 women with breast cancer before, during, and after RT. The study was part of a larger cohort study: “Advancing the science of symptom management and support for cancer patients and their caregivers”, which investigated symptoms and symptom clusters for patients and their family caregivers. Since the study was part of a larger cohort study, several decisions had already been made in respect to both study design and data collection. The “Theory of Unpleasant Symptoms” (TOUS) has been used when writing this dissertation, both as a helpful tool and framework in selecting variables for the analyses and in interpreting the complexity of symptoms (23).

In summary, the main theme of this dissertation is the patient-reported outcomes for women with breast cancer before, during and after RT. The present study has investigated the high symptom burden for these women, how it changes over time, the various dimensions of the symptoms, what predicts the symptoms, and finally how the symptom burden affects QOL.

1.1 Breast cancer – definitions and treatment

1.1.1 Stage of disease

Staging of breast cancer tumors is based on whether the cancer is invasive or non-invasive and the size of the primary tumor (T), whether lymph nodes are involved (N), and whether the cancer has spread beyond the breast (M) (Table 1) (24). The TNM stages are then grouped into stages (Table 2). The stage of disease are used for understanding the prognosis of the patient, to guide treatment decisions, and to provide a common way to describe the extent of breast cancer, so that results can be compared and understood across countries.

Table 1 TNM Staging System for Breast Cancer

Primary Tumor (T)

TX	Primary tumor cannot be assessed
T0	No evidence of primary tumor
Tis	Carcinoma in situ
T1	Tumor ≤ 20 mm in greatest dimension
T2	Tumor >20 mm but ≤ 50 mm in greatest dimension
T3	Tumor >50 mm in greatest dimension
T4	Tumor of any size with direct extension to the chest wall, and/or to the skin (ulceration or skin nodules)
<i>Note:</i> Invasion of the dermis alone does not qualify as T4	

Regional Lymph Nodes (N)

NX	Regional lymph nodes cannot be assessed (e.g., previously removed)
N0	No regional lymph node metastases
N1	Metastases to movable ipsilateral level I, II axillary lymph node(s)
N2	Metastases in ipsilateral level I, II axillary lymph nodes that are clinically fixed or matted; or in clinically detected * ipsilateral internal mammary nodes in the <i>absence</i> of clinically evident axillary lymph node metastases
N3	Metastases in ipsilateral infraclavicular (level III axillary) Lymph - node(s) with or without level I, II axillary lymph node involvement; or in clinically detected *ipsilateral internal mammary lymph node(s) with clinically evident level I, II axillary lymph node metastases; or metastases in ipsilateral supraclavicular lymph node(s) with or without axillary or internal mammary lymph node involvement

Distant Metastases (M)

M0	No clinical or radiographic evidence of distant metastases
M1	Distant detectable metastases as determined by classic clinical and radiographic means and/or histologically proven larger than 0.2 mm

Table 2 TNM Staging Grouping for Breast Cancer

Staging Grouping			
0	Tis	N0	M0
I	T1*	N0	M0
IIA	T0 – T1*	N1	M0
T2	N0	M0	
IIB	T2	N1	M0
T3	N0	M0	
IIIA	T0 – T2	N2	M0
T3	N1 - N2	M0	
IIIB	T4	N0 – N3	M0
IIIC	Any T	N3	M0
IV	Any T	Any N	M1

*Used with the permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original source for this material is the AJCC Cancer Staging Manual, Seventh Edition (2010) published by Springer Science and Business Media LLC, www.springer.com.
T1 includes T1 mic.

Breast cancer can occur bilaterally, most commonly in patients with infiltrating lobular carcinoma (25;26). The incidence of primary breast cancer in the contralateral breast or synchronous bilateral breast cancer is low, but has a negative impact on the prognosis (25;26).

1.1.2 Treatment

National guidelines for the treatment of breast cancer have existed in Norway since 1981, aimed at ensuring uniform cancer treatment of high quality for the patient group (27). In localized breast cancer, the goal is always curative, while with metastatic (distant) disease there is no curative option. The treatment is influenced by clinical characteristics (age, menopausal status, stage of disease) and pathology features. Treatment is commonly multimodal, with combinations of surgery, RT, CTX, hormones and antibody therapy (4-7). In the guidelines, a strict flow diagram

describes the standard choice of treatment in the multiple different patient subgroups.

1.1.3 Surgery

The goal of surgery is to achieve local control, before metastasis occurs. Surgical options are breast – conserving surgery (BCS) or mastectomy. The decision on mastectomy is influenced by both medical and psychological factors, and more women seem to choose mastectomy when reconstruction is conducted during the same procedure (28;29).

Sentinel lymph node biopsy (SLNB) is the initial standard axillary lymph node staging procedure for women with invasive breast cancer. In the case of large tumors or known metastases to lymph nodes, a routine axillary lymph node dissection (ALND) is performed without previous SLNB. In ALND, a minimum of 10 lymph nodes are removed, most often at the same time as BCS or mastectomy (27;28;30).

1.1.4 Radiotherapy

RT is given postoperatively after BCS. The main goal is to reduce the risk of local or distant relapse, and thereby to increase survival (6;7). The most common site of recurrence after BCS is the conserved breast, and post-operative RT is therefore recommended for the whole breast. RT is recommended after mastectomy if microscopic resection margins are positive (with tumor cells) or uncertain. Furthermore, RT is recommended for patients with metastases of at least 2mm in an axillary lymph node, breast cancer stage III, or occasionally without previous surgery in patients with very large tumors or inflammatory breast cancer (6;7;27).

1.1.5 Chemotherapy

Several CTX regimens are used. Combining cytostatic drugs (polychemotherapy) has proved more effective than using one drug alone (27;31-33). The choice of CTX

regimen for each patient depends on a number of complex clinical considerations (age, menopausal status, HER2 status, proliferation status (Ki67)) (27;31;34).

1.1.6 Hormonal and antibody therapy

In patients with estrogen- and/or progesterone-receptor-positive tumors, hormonal treatment has considerable effects on survival (32;33). Hormonal therapies affect hormone-receptor-positive breast cancer in two ways: by lowering the amount of estrogen in the body, or by blocking the action of estrogen breast cancer cells. Types of hormonal therapies include aromatase inhibitors, selective estrogen receptors, and estrogen receptor down regulators (27;31;33).

Antibody therapy/immunotherapy is given to patients with specific characteristics of the cancer cells, such as a protein that causes cancer cells to grow in a rapid and abnormal way (HER2-positive) (27;31;32).

1.2 Background

1.2.1 Literature Search

Systematic searches were conducted, based on two main topics with the following search terms:

1. Symptoms – breast cancer – radiotherapy
2. Quality of life (QOL) – breast cancer – radiotherapy

For all searches, the following multiple relevant multidisciplinary electronic databases were used: MEDLINE/Ovid, PsychINFO/Ovid, CINAHL. Every term was searched for using both the thesaurus of the databases and the free text/key word method. In addition, manual searches of reference lists were an important contribution to retrieving all available and relevant literature. The literature searches were conducted in collaboration with a medical librarian.

1.2.1 Symptoms – definitions

Symptoms are defined as “the perceived indicators of change in normal functioning as experienced by patients” (Rhodes and Watson, 1987, p. 242) (35). The definition is based on a subjective measurement, and it implies that the symptom can only truly be known and described by the person experiencing it. Therefore, symptoms should be reported by the individuals who experience the symptoms themselves.

Each specific symptom has several measurable dimensions (e.g., frequency/timing, severity/intensity, distress). These different dimensions are referred to as the *multiple dimensions* of a symptom, and are described to add valuable information about the symptom experience, in contrast to only reporting its occurrence (23;36)

Recent evidence suggests that women who receive treatment for breast cancer experience multiple symptoms, rather than individual symptoms (20-22). Each of the different treatments represents a risk of several treatment-related symptoms.

After surgery, the women most commonly describe symptoms such as pain, lymphedema and fatigue (9;11). CTX in these patients is associated with a number of symptoms, often occurring simultaneously. Fatigue is the most commonly reported symptom(8;16;17;37). Nausea, hair loss, a sore mouth, taste and appetite change, diarrhea, and constipation are other commonly reported symptoms for women receiving CTX for breast cancer (13;16;38-40). RT is associated with additional symptoms (e.g., fatigue, swelling of breast and pain) for women with breast cancer while menopausal symptoms such as hot flashes, difficulty sleeping, and fatigue are commonly described by women receiving hormones (39;41-45).

The conceptualizations of multiple symptoms that occur concurrently have been given considerable attention in the symptom literature for cancer patients in general and for patients with breast cancer in particular. A ‘symptom cluster’ is defined as three or more concurrent symptoms that are related to each other (46). Investigating symptom clusters in a variety of different cancer diagnoses (i.e., breast, ovarian, head and neck, and colorectal cancer) was one of the main aims for the larger cohort study that this dissertation is based on. This dissertation is not focused

on symptom clusters, but on multiple symptoms that women experience before, during and after RT for breast cancer. A set of multiple symptoms may differ from a symptom cluster, by including symptoms that occur simultaneously, while the symptoms within a symptom cluster must be related to each other, sharing the same etiology. The focus of the dissertation was the symptom burden of multiple symptoms experienced by patients in relation to RT.

1.2.2 Symptoms – literature review

Early in the research process, a gap in the literature describing multiple symptoms for women who are receiving RT for breast cancer was detected. The majority of papers focused on individual symptoms (e.g., fatigue, nausea, or pain), even though women with breast cancer more commonly suffer from multiple symptoms (20-22). In addition, most literature was found to investigate only single dimensions of a symptom (e.g., distress or frequency) in contrast to investigating the various dimensions of the symptom (e.g., frequency, severity, and distress). The vast majority of the literature described symptoms for this patient group post treatment and not during treatment. Finally, few studies were found to investigate symptoms longitudinally during the course of RT. A summary of the literature is presented below.

Longitudinal studies of multiple symptoms

Only four prospective longitudinal studies investigated symptoms longitudinally for women with breast cancer during RT (10;40;45;47), and three different symptom inventories were used to measure symptoms.

For three of the studies (10;40;45) an increase in symptom experience and symptom severity during the course of RT was found. Wengstrom et al. (2000), who investigated symptoms, side effects and QOL for women with breast cancer (n = 134) during and following RT, found an increase in symptoms and their severity during treatment (40). This finding has been supported in more recent studies (10;45).

Further, the study by Wengstrom et al. found that symptoms slowly decreased to pre-treatment levels within three months after the last RT session (40). Similar findings were made in a convenience sample of 30 women with breast cancer conducted by Knobf et al. (10), who also found an improvement within three months after last RT. In contrast, a study investigating the occurrence and burden of side effects during and after RT for breast cancer (n = 171) found that the total burden of side effects remained higher six months after the last RT sessions (45).

In a retrospective study, Warmer et al. (47) investigated multiple symptoms two weeks, three months and 12 months after treatment of early breast cancer (n = 329). They found that the addition of RT and/or CTX to surgery made little difference to symptoms reported (47).

In summary, the literature describing multiple symptoms longitudinally during RT is scarce, and highlights the need for additional research.

Multiple symptoms in heterogeneous cancer samples

Seven more studies (48-54) investigated symptoms for women with breast cancer as part of a heterogeneous sample. Portenoy et al. (48) investigated symptom prevalence, characteristics and distress in a heterogeneous sample of cancer patients (n = 243), including women with breast cancer (n = 70). In the latter study, the number of symptoms was found to be strongly associated with heightened psychological distress and poorer QOL. However, the study was of cross-sectional design, and almost two-thirds of the sample had metastatic disease.

Munro and Potter (49) investigated distress caused by symptoms after radical RT in a heterogeneous sample of cancer patients (n = 110), including 72 patients with breast cancer. The study found that the most frequent symptoms did not necessarily cause the most distress. For women with breast cancer, significant changes were found in symptoms during the course of RT. Tiredness was found to increase between weeks two and three of the treatment, and returned to pre-treatment level at the first follow-up visit (week 7 after pre-treatment data). The distress related to certain symptoms (numbness, worry about effects of the disease and treatment on

family members, and feeling anxious) decreased between the initial assessment and the follow-up.

Several of the papers (50-54) described validation of a symptom inventory in different languages, all using cross-sectional design. Women with breast cancer represented from 10 % to 36 % of the samples, and fatigue was rated as the most severe symptom in all the studies.

In summary, the literature describing multiple symptoms in women with breast cancer includes studies with both cross-sectional and longitudinal design, the use of several different symptom inventories, and variations in study samples, which makes it difficult to summarize the results.

1.2.3 Quality of life – definitions

There is not one universally agreed definition of QOL, and clear definitions are not often presented in publications. QOL could be defined as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with areas of life that are important to him/her” (Ferrans 1990, page 249) (55). The definition is based on a subjective measurement, and implies that QOL can only truly be known and described by the person experiencing it, and should therefore be self-reported.

In health science, QOL is regarded as a multidimensional concept that includes several areas of life affected by disease and treatment. A health-related QOL inventory may include some or all of the following dimensions: psychological/emotional functioning, physical functioning, social functioning, disease specific symptoms/pain, vitality, social functioning, treatment-related side-effects, and spiritual aspects (56-58). QOL inventories can either be generic or specific to a disease. A disease-specific questionnaire will include disease- and treatment-specific characteristics, and can therefore not be used for other populations. A generic QOL inventory does not include disease-specific questions, and can therefore be used and compared across populations.

Health Related Quality of Life and QOL are used interchangeably in the cancer and symptom literature. In the current dissertation, QOL refers to both terms.

1.2.4 Quality of life – literature review

The number of research papers on women with breast cancer and QOL is substantial. However, the literature describing QOL in relation to RT in this patient group is more limited, with 12 identified studies (40;59-69). Single symptoms (e.g., pain, fatigue, nausea) and their effect on QOL have been well studied. However, this is not part of the scientific background for the current study, where the effect of multiple symptoms was the scope of interest. Different factors (e.g., demographic, clinical, and treatment) that influence QOL for women receiving RT for breast cancer have been described in some studies (66-69), as well as the effect of multiple symptoms (40;59;62;64;65) on QOL. A review of the literature is presented below.

Radiotherapy has minimal effect on quality of life for women with breast cancer

Four studies (59-62) found that RT had a minimal effect on QOL during or shortly after the course of RT.

In one study (n = 175), no negative effects on QOL from baseline (start of RT) to six weeks after commencing RT were found (60). Similarly, in another study by Lee et al. (2008) (n = 61), QOL was assessed at baseline, at the end of RT, and seven months after the completion of RT (59); no changes in QOL were found. Fatigue and breast symptoms increased during RT, but returned to baseline levels after seven months. However, fatigue was found to be the strongest predictor for poorer QOL after RT in this study (59).

Reidunsdatter et al. (62) investigated early effects of RT on QOL and explored treatment-related contributors to the development of fatigue during RT (n = 248). Data were collected before the start of RT (baseline) and immediately after the end of RT. RT had limited effect on QOL, but breast symptoms and fatigue increased significantly during RT, as in the study by Lee et al. (59).

Radiotherapy has effect on quality of life for women with breast cancer

Other studies (40;61;63-65) investigating QOL during and after the course of RT found a change in QOL during the course of RT. A study conducted by Whelan et al. (2000), using data from a clinical trial running between 1984 and 1989 (n = 416), evaluated the effect of RT on QOL, by comparing the treatment group (RT) with a control group that did not receive RT after undergoing lumpectomy and ALND. QOL was measured at the start of treatment, as well as one month and two months thereafter. RT had a negative effect on QOL during treatment; however the RT regimen used in this study is no longer commonly used (63). Wengstrom et al (2000) conducted a study where the purpose was to describe symptoms, side effects and QOL of women with breast cancer (n = 134) during and following RT (40). In this study, QOL was found to be poorest at baseline before treatment had started, and an improvement was seen after the completion of treatment. As in the other studies an increase in symptoms and their severity as the treatment progressed was found (40).

Browall et al. (64) found a decreasing tendency in QOL during the course of RT for women with breast cancer (n = 150) (64). The general finding from the latter study was that adjuvant treatment was associated with decrease in overall QOL, physical and role functioning, and body image, and an increase in anxiety as well as in several other symptoms. Budischewski et al. conducted a study where the aim was to evaluate for changes in QOL during the course of RT, with a focus on subgroup analyses of patients with unchanged, increased or decreased QOL (65). The sample consisted of 61 women with breast cancer receiving RT for breast cancer, and QOL was measured three times: at the beginning of RT, in the fourth week and six weeks after the end of treatment. The interpretation of these data is difficult, due to the small sample size, but 15 patients described a decrease in QOL, while 25 and 21 patients described increased or no changes in QOL, respectively.

Finally, a study conducted by Deshields et al (2005), investigating the course of emotional adjustment and QOL among breast cancer survivors (n = 94)

immediately following RT, found that participants reported elevated levels of depression, low levels of anxiety and diminished QOL at the end of treatment. However, both QOL and depression improved significantly within two weeks after treatment, before they stabilized (61).

Predictors of quality of life among women with breast cancer receiving radiotherapy

Four studies investigated predictors of QOL during RT (66-69). In a longitudinal study of women with breast cancer after BCT during and after RT (n = 109), QOL was assessed at the beginning, at the end, and six weeks after RT (66). The findings from this study revealed that CTX significantly lowered QOL compared to hormonal therapy or RT alone. Another study conducted by Hopwood et al. (2007) investigated the impact of age and other cancer treatments on QOL for women receiving RT for breast cancer (n = 2208) (67). This study found CTX together with age to be a risk factor for poorer QOL for women about to start RT (67). In a study including 1057 newly diagnosed patients with either breast cancer (n = 627) or prostate cancer (n = 430), RT was not a significant predictor of diminished QOL (68). In the same study, women who received CTX and had played a more passive role in the treatment decision-making were found to have significantly greater distress and lower QOL at 12 weeks consultation after treatment consultation.

Another study by Munshi et al. (2010) compared QOL in women with breast cancer (n = 113) treated with mastectomy and RT versus BCS and RT (69), at baseline (pre-RT), midway in RT, and at the end of RT. The study found no significant differences in QOL between the mastectomy and the BCS group, and no significant change in QOL after RT in both groups (69).

It is difficult to summarize the results from previous publications on QOL for women receiving RT for breast cancer, as the studies vary in design, sample sizes, and QOL inventories, and show conflicting results. It seems that RT in itself has limited effect on QOL, but the results have been conflicting.

1.3 Theoretical framework – the Theory of Unpleasant Symptoms

For the larger cohort study, of which this study is a part, the Theory of Symptom Management (70) served as the theoretical framework, and was also used in the first publication of this dissertation. However, the theoretical framework used for this study is the theory of unpleasant symptoms (TOUS) by Lenz and Pugh (1997) which was found to be more appropriate for the present study, as it captures several aspects of the symptom experience that were investigated in the present study (23). Based on the paper by Lenz and Pugh (1997) the TOUS will be presented below (23).

The purpose of the theory is to improve understanding of symptom experience in various clinical situations, and in turn to diminish negative effects of the symptoms experienced.

The theory was first designed to integrate existing knowledge about different symptoms, with the premise that there are similarities across different symptoms, and it provides common definitions and dimensions for examining symptoms. The TOUS was first published in *Advances in Nursing Science* in 1995 (71). A revised version (23) emphasizes that symptoms can either occur alone, or in combination with other symptoms (multiple symptoms) (Figure 1). Further, the TOUS describes that multiple symptoms can either occur as a result of a single event (e.g., physiological factors such as CTX), or that one symptom can lead to another symptom (e.g., anxiety may result in sleep disorders), (Figure 1). The theory consists of three major concepts; the symptom, influencing factors and performance outcomes (Figure 1).

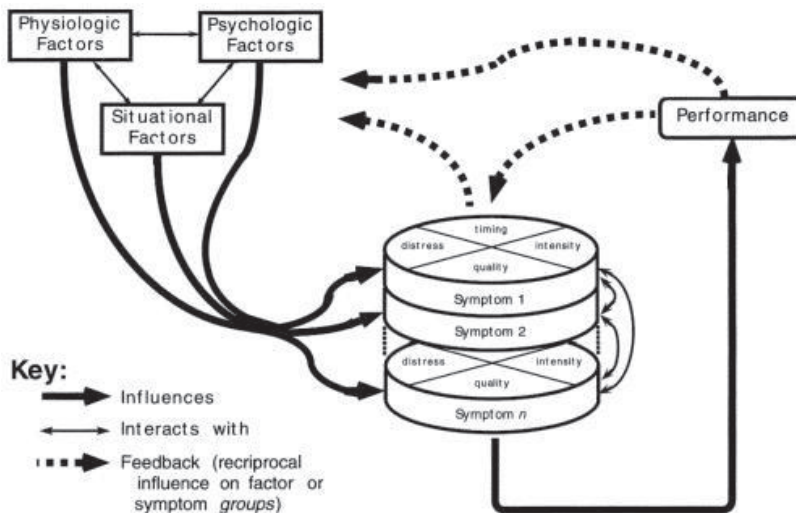


Figure 1 The Theory of Unpleasant Symptoms (TOUS)

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The theory describes the symptoms to vary in intensity, degree of distress, timing and quality. The *intensity* dimension can also be described as the severity or the strength of the symptom. Intensity is described to be the simplest aspect of the symptoms to rate according to the TOUS, and is frequently used in clinical situations (e.g., pain on a scale from 0-10). The *time* dimension includes the way symptoms vary in duration and frequency. Duration describes the length of time the symptom continues, and also how often it occurs. It is common to differentiate acute from chronic symptoms, and they are often also treated differently. According to the model, the *distress* dimension reflects to which degree an individual are bothered by the symptom, and further refers to the meaning that the individual gives the symptom. The final dimension of the symptom described in the TOUS is *quality*. By including this dimension the theory includes a personal aspect in the description of symptoms, as the different symptoms will be described differently for the various symptoms (e.g., sticking for pain). This aspect will need a qualitative approach, if captured in research, and the patients must be able to describe the experience of the symptom.

The influencing factors of the symptoms (Figure 1), are identified by Lenz & Pugh to be physiological factors, psychological factors, and situational factors. *The physiological factors* involve anatomical, physiological, genetic, and treatment-related variables, and are described to influence the occurrence of symptoms and how it is experienced. In the present study several of the physiological factors (stage of disease, comorbidities, treatment variables, and age) were investigated as predictors of the symptoms and its trajectory using regression models. *Psychological factors* are described as one of the more complex components of the model, and include both affective and cognitive variables. These factors will possibly affect the individual response to the symptom and could possibly intensify it (e.g., anxiety, anger, depression). *Situational factors* cover the individuals' environment, both social and physical. Examples of situational factors are marital status, socioeconomic status, lifestyle behaviours (exercise, smoking, alcohol consumption), and social support. The physical environment (humidity, pollution, noise etc.) is also described to influence the experience of symptoms in the TOUS. Several of the social factors of the patients' lives have been investigated (marital status, education, employment status) in the present study. All of the three influencing factors may interact with each other, as well as they influence the symptom experience.

Lenz and Pugh have defined the outcome of the above concepts as *performance* (Figure 1), and is described as the consequences of the symptom experience. A symptom or set of symptoms may give a number of different performance outcomes (e.g., physical impairment, changes in work situation, QOL), and is based on the assumption that the experience of symptoms can have an impact on a person's ability to function. The performance status is described to possible have a feedback effect on both the situational factors and directly at the symptoms by the model.

In the present study, the influencing factors, the various dimensions and the performance outcome of the symptoms has been investigated.

2.0 Aims of the study

The main aim of this study was to investigate the various dimensions of multiple symptoms and QOL for women receiving RT for breast cancer.

More specific, the following research questions have been explored in the dissertation;

1. Describe the differences in symptom occurrence, frequency and distress for women with breast cancer who have undergone surgery, based on whether they have received CTX or not (Paper I)
2. Investigate predictors for total number of symptoms for women who have had surgery for breast cancer (Paper I)
3. Describe QOL before start of RT based on whether they have received CTX or not (Paper I)
4. Investigate changes over time in occurrence, severity, and distress of common symptoms during and after RT for breast cancer patients (Paper II)
5. Evaluate predictors for the various dimensions (occurrence, severity, distress) of common symptoms during and after RT for breast cancer patients (Paper II)
6. Evaluate predictors of change over time for the various dimensions (occurrence, severity, distress) of common symptoms during and after RT for breast cancer patients (Paper II)
7. Evaluate predictors for the level of QOL through the course of RT for women with breast cancer after surgery (Paper III)
8. Evaluate predictors of change in QOL through the course of RT for women with breast cancer after surgery (Paper III)

3.0 Methods

3.1 Study design

This longitudinal descriptive study is part of a larger cohort study investigating symptoms and symptom clusters in oncology patients and their family caregivers. The main study collected data on four different cancer diagnoses (i.e., colon-, ovarian-, head and neck-, and breast cancer) and their caregivers, and had a six months follow-up. Clinical and QOL data were collected at five (breast and head and neck cancer) or eight (colon- and ovarian cancer) time points for patients, and at three time points for the caregivers. In addition, blood samples were taken for genetic analyses to be used in the main study. The timing for data collecting was chosen in order to be able to capture the expected maximum increase in symptom burden after treatment.

Breast cancer patients were recruited at the RT department, Oslo University Hospital, Norwegian Radium Hospital from December 2008 until June 2009.

3.2 Patient recruitment

A team consisting of three study nurses and the PhD student recruited patients to the study. The patients were first introduced to the study by one of the clinical nurses at the RT outpatient clinic eight days prior to the start of RT. These nurses were trained in approaching the patients, giving all patients similar information. Potential study participants were then introduced to one of the members of the recruitment team. When patients agreed upon being approached, they were given both written and oral information about the study. After signing the consent form, they were enrolled into the study, and given a study identity number. A valid baseline measurement was compulsory, and all patients, who signed the consent form but did not fill out the questionnaires within four weeks, were excluded from the study.

3.3 Inclusion and exclusion criteria

Patients were invited to participate if they were adults (≥ 18 years of age); able to read, write and understand Norwegian; and scheduled to receive RT for breast cancer or ductal carcinoma in situ (DCIS). Patients were excluded if they were to receive RT to the brain or had a disease that affected their cognitive ability and if they did not fill in the baseline questionnaire.

3.4 Data collection and follow-up

When the consent form was signed, each patient received the first package of 10 questionnaires. Five of the questionnaires were used for this dissertation, and will be presented below (chapter 3.6). At the predefined time points, new questionnaires were sent home to the participants by post. If patients did not fill out the questionnaires, one reminder was sent out by post for each time point.

Baseline (Time 1) in the present study was approximately one week prior to the start of RT. The first follow-up (Time 2) was one month after baseline, and the next assessment (Time 3) was after one additional month. Assessment points four (Time 4) and five (Time 5) were three and six months after baseline respectively, and were intended to capture the longitudinal perspective of the RT.

Age, stage of disease, treatment goal (curative/palliative), treatment status (i.e., primary treatment, recurrence, progression), and types of previous treatments were obtained by the research team from the medical record and documented in case report forms (CRFs). Different nurses and doctors, often at the local hospitals, filled out the CRFs for clinical data six months after inclusion. In order to obtain consistency in the data collection, there was a guide on how to fill out CRFs, both at baseline and at six months after baseline. Previous cancer treatments were categorized as surgery (i.e., mastectomy, BCS, ALND, SNLB, other), CTX, RT, hormonal therapy, immunotherapy, or other. Information on distant metastases was also collected (i.e., lymph nodes, skeleton, brain, liver, lung, peritoneum, other). In the CRF after six months, information on recurrence (yes/no), total dose and number of fractions of RT, as well as area of RT were collected. Information on other

treatments over the six-month follow-up periods was also reported (i.e., CTX, hormonal therapy, immunotherapy, surgery). Finally, data on disease status (i.e., alive-tumor free, alive-tumor free after treatment for recurrence, alive-stable disease, alive-progression, never tumor free after treatment for primary cancer or recurrent disease) and death (i.e., death-index tumor, death-other disease with active tumor, death-other disease and tumor free, death-unknown) were collected.

3.5 Data handling and initial quality assurance

The questionnaires and CRFs were electronically scanned by a research facility office, Kontor for Klinisk Forskning (KKF) at the Norwegian Radium Hospital. The routines for scanning were discussed with the staff, in order to maintain high compliance in all steps of the research process. When boxes within the questionnaires had been left open, if an X or tick was placed between two boxes, or if several boxes were ticked in one line, the machine stopped and the data was manually checked. Both empty boxes and X's between two boxes were registered as missing items. If patients ticked several boxes for education, the box for the highest level of education was used. The machine also stopped if there was additional writing; this had to be typed in manually. All the data entry and CRFs were double-checked by the staff at KKF. When all data files were complete, an additional quality assurance was initially performed by checking 10 % of the charts against the paper version of both the CRFs and the questionnaires. Due to the level of errors detected, all 188 cases at all five time points and all CRFs were double-checked manually against the paper versions, and corrected when needed.

3.6 Instruments

Patients were asked to fill out a package of 10 questionnaires (a demographic questionnaire, comorbidity score, performance status, symptom inventory, pain inventory, two QOL measures, sleep disorder, depression scale, and fatigue scale). For this dissertation, results from five of the questionnaires (demographic

questionnaire, comorbidity score, performance status, symptom inventory, and one QOL inventory) were used to answer the research questions in the present study, and are presented below.

A pilot study was conducted before the data collection started. The purpose of the pilot study was three fold: 1) to find out how much time the patients used to fill out the whole package of 10 questionnaires, 2) to test the logistics in the data collection process, and 3) to get feedback on a questionnaire we had translated into Norwegian (see 3.6.4). More details on the translation process will be given below. Ten patients with cancer (i.e., ovarian, colon rectal, breast, head and neck cancer, and lymphoma), comprising six women and four men, were recruited to the pilot study. The patients took between 8 and 35 minutes to fill out the 10 questionnaires.

3.6.1 Demographics

Patients provided information on marital status (married, partnered or unmarried/divorced/widowed), living situation (living alone or with someone, including children), level of education (primary, secondary, college/university), and employment status (full/part time, sick-leave/disability benefit, retired/other). Only baseline data on the demographic variables have been used in the present study.

3.6.2 Karnofsky Performance Status Scale (KPS)

Physical functioning was assessed by self-report, using the KPS. This scale is extensively used to evaluate the performance status of an individual cancer patient both in clinical practice and in research. The KPS has a well-established construct validity and reliability and it is considered a global indicator for functional status in cancer patients (72-74). The Norwegian version has been used in several Norwegian studies of cancer patients (75-77). The KPS score ranges from 0 (death) to 100 (the individual is able to carry on normal activities). As patients in this study were

outpatients, the range of the scale from 40 (disabled and need of special care) to 100 was used. The patients were asked to fill out the KPS at all five time points.

3.6.3 Self-Administered Comorbidity Questionnaire (SCQ – 19)

Information on comorbidities was obtained through self-report using the SCQ-19 (78). The number of, treatments for, and functional impact of health problems were evaluated by listing 16 common comorbidities and three optional conditions. Patients were asked to indicate whether they had the co-morbid condition (yes/no); if they had the condition, they were asked if they were receiving treatment for it (yes/no); and finally, if it limited their activities (yes/no). The total SCQ-19 score range from 0 to 57 when the three optional items are used (78). A higher total score indicates a more severe co-morbidity profile. The SCQ has established validity and reliability for the assessment of comorbidities in patients with chronic medical conditions (78) and has been used in previous studies in Norway (75;79).

Patients were coded as having the co-morbid condition if any of the three boxes were checked (i.e., if they had the condition, if they received treatment for it, or if it limited their activities), even if the patient had checked 'no' on 'do you have the comorbid condition'. A sum score of the SCQ was used in the present study. The patients were asked to fill out the SCQ at baseline, and at three and six months after baseline, and data from all time points have been used in the present study.

3.6.4 Memorial Symptom Assessment Scale (MSAS)

The MSAS was used to obtain data on the patients' symptoms, and is one of the important outcome measures in the study, together with QOL. The MSAS contains a list of 32 physical and psychological symptoms (36). For each symptom, patients are asked to indicate whether or not they had the symptom during the past week (i.e., occurrence). If they have experienced the symptom, they are asked to rate its frequency (not used in our analyses), severity, and distress. Severity is rated using a four - point Likert Scale (i.e., 1 = slight, 2 = moderate, 3 = severe, 4 = very severe),

while symptom distress is rated using a five-point Likert scale (i.e., 0 = not at all, 1 = mild, 2 = moderate, 3 = severe, 4 = very severe).

The MSAS has three valid subscales (i.e., Global Distress-Index, a psychological symptoms subscale (PSYCH), and a physical subscale) (36).

The reliability and validity of the instrument is well described in Portenoy's original work (36), and the instrument has been extensively used internationally (48;80-86).

In the analysis of these data, patients were coded as having the symptom if one or more of the boxes were checked (i.e., frequency, severity, or distress) even if the patient had checked "do not have" the symptom. We followed the same procedures as done in other studies (87;88). Missing items were coded as the patient did not have the symptom. The present study did not use any of the three valid subscales developed for the instrument, as we were interested in the frequency and mean scores of occurrence, severity, and distress, of the reported symptoms.

In the present study the occurrence rate (i.e., total number of symptoms) as well as the mean severity and distress scores have been reported and used in the regression analyses. The patients were asked to fill out the MSAS five times, and all five time points have been used in the present study.

3.6.5 Translating the MSAS into Norwegian

The MSAS was translated into a Norwegian version using a standard forward-backward translation, based on MAPI Institute guidelines (89), after receiving permission from the developer of the instrument (Dr. Portenoy). Four bilingual health care providers individually translated the English version into Norwegian. After the translations, all four met for discussion and transformation of the four versions into one. Minor disagreements were resolved through discussion. The unified Norwegian version was then sent to a professional translator for a back translation into English. The back-translated English version was sent to the developer of the instrument, asking for comments. The next step in the process was to pilot test the Norwegian version of the MSAS, as described above. The patients did not comment on or have any questions regarding the questionnaire (MSAS).

Unfortunately, the Norwegian version contained a column asking the patients to rate the frequency of the last eight symptoms in the questionnaire, while the original version did not. The issue has been discussed with Dr. Portenoy, and the instrument was used without removing the frequency dimension.

Formal psychometric testing was not performed for the translated version, as the population in the present study (i.e., patients with breast cancer) was part of the population in the original paper (i.e., patients with colon, prostate, breast, or ovarian cancer) conducted by Portenoy et al. (36).

3.6.6 Short Form 12 (SF – 12)

QOL was measured using the SF-12 (Version 1) (56), which is a generic QOL measure. It was developed to provide a shorter, yet valid alternative to the frequently used MOS 36-item short form health surveys (SF-36) (90). The SF-12 contains a subset of 12 items from the SF-36, including one or two items from each of the eight subscales (e.g., physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health). Information from the 12 items is used to construct physical and mental component scores (PCS and MCS) (91). The scoring scheme for SF-12 (V1) does not allow any missing data in the 12 items. The sum score is calculated only if all 12 items have valid responses. The SF-12 PCS and MCS summary measures are scored using norm-based methods from the 1998 general United States (U.S.) population, with a mean of 50 and a SD of 10. The implication is that scores above or below 50 are interpreted as being above or below the mean scores in the general U.S. population (91;92). The advantage of the standardization and norm-based scoring of the PCS and MCS is that results for one summary score can be compared with results for the other and the scores have a direct interpretation in relation to the distribution of scores in the general U.S. population. These scores are similar to cut-off scores for the Norwegian general population (i.e., mean PCS 50.3, SD 8.8 and mean MCS 50.6, SD 9.9) (57). Higher PCS and MCS scores indicate better QOL. There is no general consensus on the minimum clinical significant change in the SF-12 (93).

The SF-12 has undergone extensive validity and reliability testing through cross-validation of item selection and scoring in nine countries (57) and has been widely used for cancer patients (87;94;95). The Norwegian version is the result of a comprehensive translation of the original, and has satisfactory validity and reliability in Norwegian cancer patients (57;93). We did not perform reliability testing for the specific study sample. Cronbach's alpha is not really appropriate for the two-component scores of the SF-12 (V1), because the two-component scores are based on different weights and factor analysis loadings, and they are not the same for every item (91).

The patients were asked to fill out the SF-12 five times, and all five time points have been used in the present study.

3.7 Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics (REK) (154-081158d 6.2008.547), the Norwegian Directorate of Health (08/6788), the Privacy Protection Committee at the hospital (08/1194), and the institutional review board at the Norwegian Radium Hospital.

In the first application to REK, the follow-up period was planned to be 12 months. However, REK considered that participation in a study for such a long period was a potential burden for patients, and the study was only given permission for a 6-month follow-up period. This compromised the data from the study, as we were interested in long-term symptoms and QOL.

When recruited to the study, the patients were first asked by the staff if they wanted to receive information about the study, and even receiving information about the study was therefore voluntary. The recruitment team was not allowed to access the medical files with the purpose of identifying patients who met the inclusion criteria of the study; therefore one of the staff had to identify the eligible patients from the medical files.

The PhD student or a research nurse obtained informed consent before the start of RT. All patients who were invited to participate had the opportunity to

consider the issue for more than 24 hours before they signed the consent form. The consent form included the date and signature. The patients were informed that they could withdraw from the study at any time during the study period, without giving reasons.

Data protection was looked after in the present study. When patients had signed the consent form, they were all given a unique study identity number. All patient information (i.e., questionnaires, CRFs) was treated without personal data (i.e., national identity number) or other information that could identify the patients. The unique study identity number was used on all data, and the codebook that coupled the study identity number to the patients, was locked into a separate locker from the data.

3.8 Statistics

3.8.1 Overall considerations

Paper I in this dissertation was limited to baseline data, while paper II and III present longitudinal data over six months.

Mixed-model analyses were used for the longitudinal analyses in this dissertation. The models in mixed-model analyses consist of subject-specific effects (mixed effects). The analyses further allow for unequal number of observations on each subject, meaning that a complete dataset was not required for running the analyses (96). The mixed-model analyses were also used because of the repeated measures (more than one for each individual) and since the missing data were considered as missing at random (96;97). Cases with a lot of missing data on a predictor were dropped from the analyses. Mixed-model analyses allow the use of all observations even if some assessments are missing, but only for the dependent variable. Missing data were further handled as described for each instrument.

In papers II and III, different mixed-model analyses were used to investigate changes over time for specific symptoms and QOL, respectively. In paper II, two different multilevel generalized linear models were used: multilevel logistic regression was used to investigate symptom occurrence longitudinally while severity

and distress were examined using multilevel proportional odds ordinal logistic regression because they both are coded as ordinal variables. For paper III, random intercept and slope models were used to analyze changes in QOL during the six months, as these models have become the standard way of analyzing continuous longitudinal data.

All analyses were done using SPSS Version 16-18 (SPSS Inc, Chicago, IL, USA), Stata Version 11.0- 11.1 (Stata Corp, 2010) (98;99). The multilevel ordinal regression models were estimated with *gllamm*, a user-written program for Stata, downloaded within Stata with “findit gllamm”(100). The figure was made in Microsoft Excel for Windows (2003). For all tests, a p-value of <0.05 was considered as statistically significant.

3.8.2 Sample size calculation

As this study is part of a larger cohort study, the sample size was based on genetic tests from blood samples in the total sample. A sample size of 500 in the larger cohort study would give greater than 80 % power to detect a significant difference ($\alpha=0.05$), and the presented *p*-values were two-sided. Specific sample size calculations are not recommended after data collection (101) and they were not performed for the subsample analyses presented in this dissertation.

3.8.3 Paper I – analyses

In the current paper, baseline data from the MSAS and the SF-12 in addition to medical and socio-demographic data were used.

Descriptive statistics were used to present demographic and clinical characteristics of the data, and independent t-test and exact chi square were used to test for differences between patients who did and did not receive CTX prior to RT. A negative binomial regression was performed to investigate the variables that influenced the total number of symptoms at baseline. Negative binomial regression was chosen rather than Poisson regression because the distribution of the symptoms

reported by the patients was strongly right-skewed with over-dispersion (the variance was greater than the mean). Selected variables (demographic and clinical) were examined, and variables that had a bivariate association (Pearson correlation) \geq than .20 with the dependent variable (total number of symptoms) were selected for joint entry into the regression analysis based on the belief that this level of association was meaningful in this exploratory study (102). The variables investigated for the model were age, level of education, employment, KPS, time since surgery, comorbidities, and type of surgery (i.e., ALND, BCS, SLNB, mastectomy). The stage of disease was not entered into the regression analysis because of its high correlation with other covariates (i.e., ALND, CTX). The variable selection was both empirically and theoretically driven. To construct a model that was parsimonious, variables were removed one at a time following the recommendations of Hosmer & Lemeshow (2000) until only significant predictors remained in the final model (103). The Benjamini–Hochberg method was used to correct p-values for multiple testing. This is a less conservative test for multiple testing than the more familiar Bonferroni– test (104).

3.8.4 Paper II – analyses

In paper II, MSAS data from all five assessment time points were used in mixed-model analyses, to evaluate the occurrence, severity and distress of symptoms over time. The six symptoms that occurred in $\geq 50\%$ of the patients at the initiation of RT (i.e., lack of energy, worrying, difficulty sleeping, feeling drowsy, sweats, pain) were evaluated in the longitudinal analyses

Symptom **occurrence** was coded as a binary variable (yes = 1, no = 0) and examined using multilevel logistic regression, while symptom **severity** and **distress** items were coded as ordinal (i.e., 0 = not present and with severity/distress ratings increasing from 1 to 4 and from 1 to 5, respectively) and were examined using multilevel proportional odds ordinal logistic regression (105-109). Demographic and clinical variables that had a bivariate association (r) of $\geq .20$ with the total number of

symptoms at baseline (i.e., age, KPS score, SCQ score, ALND, previous CTX treatment) were selected for evaluation as predictors in the regression models.

For both types of models, the first assessment was treated as baseline (intercept) for the growth trajectory. Unconditional models were examined first to estimate the linear change in the symptom reports. Given the possibility that the change was not only linear, quadratic effects were examined. The change trajectory for lack of energy had two segments: baseline to two months and two to six months. Further, the change trajectory for feeling drowsy had three segments: baseline to one month, one month to three months, and three to six months. Therefore, piecewise models were examined for lack of energy and feeling drowsy (110). The other four symptoms were best fit with linear trajectories.

After the best fitting growth trajectory for each symptom had been identified, conditional models were used to examine the associations for each of the covariates (i.e., age, KPS score, SCQ score, ALND, previous CTX treatment) on the reported symptom dimensions at baseline and on the change in symptom dimensions over time (cross-level interaction). Two of the covariates (i.e., KPS, age) were reverse coded to make interpretation easier.

3.8.5 Paper III – analyses

SF-12 data from all five assessment time points were used. Random-intercept and slope models (mixed models) were used to estimate linear trends for each of the MCS and PCS of QOL. Two random-intercept and slope models were fitted for the periods from baseline to two months and from two to six months, because of the non-linear effect of the time variable.

Variables were selected for the mixed model analyses based on p-values from bivariate analyses (Pearson correlation) in combination with clinical considerations. All of the variables were entered into the initial model, and all variables that were selected for inclusion in the multivariate analyses of association were kept in the model, to adjust for possible confounders. For the symptom variable, the mean occurrence rate for the total number of symptoms was used. The stage of disease was not entered into the initial models because of its high correlation ($r \geq 0.6$) with

other treatment variables (i.e., ALND, mastectomy, BCS, CTX). Variables describing the type of surgery were also highly correlated ($r \geq 0.6$) with each other, and only one of the three variables (i.e., ALND, mastectomy, BCS) was included in the initial models. Mastectomy was included in the model describing the MCS, and ALND was included in the model describing the PCS. The rationale for including different variables in the two models were based on the knowledge that body image is an issue in women undergoing mastectomy and is therefore important as a predictor for the MCS (64;111-113) and that ALND is associated with an increased number of symptoms and lower arm morbidity (113), and as such was investigated as a predictor for the PCS.

A series of random–intercept and slope model was used to examine the contribution of the independent variables to the trends of both MCS and PCS. A likelihood ratio test, using the maximum likelihood method, was performed for variables with p -values ≥ 0.05 in the model, to identify whether a variable contributed to the model even if it was not significant. The presented values were adjusted for the covariates in the models.

4.0 Results

4.1 Participants

In the main cohort study, 613 patients and 278 family caregivers were included. Women with breast cancer (n=188) recruited for the main study were included for the secondary analyses undertaken for this doctoral dissertation.

As described in the flowchart below (Figure 2), 245 women were eligible for participation in the study, and 211 (85 %) signed the informed consent form. Two of the included patients did not have breast cancer, and they were therefore excluded from the study. For the 34 patients who declined participation, the most common reason given was that they did not like questionnaires or they did not have the energy to fill out the questionnaires. Finally, 188 patients (76 %) filled out the baseline questionnaire while 21 patients never returned it, or withdrew before they filled it out. One patient died from the index tumor during the study period. In the inclusion criteria for this study, it was not specified that the women had to be scheduled for post-operative RT, and three women with metastatic disease were included in the study. These patients received a different total dose of RT (30 Gy) compared with the women who were scheduled for post-operative RT (50-60 Gy); the mean value of the total sample was 49.6 (SD 2.6) Gy.

The sociodemographic and clinical characteristics of the participants are described in Table 3. The mean age of the patients in the study was 57.7 years (SD = 9.2), and the patients who declined participation were significantly older (mean age 61.5 years, SD = 10.8, $p = 0.015$) than the patients who agreed to participate. The majority of the women were married or living with a partner and had a primary or secondary level of education. The majority had stage I or II of the disease, while eight patients did not have a TNM classification, and five patients had cancer in both breasts.

Approximately half of the women in the sample had received CTX at the time of their inclusion in the study. Most of them had undergone BCS while 36 % had undergone mastectomy, and six patients had undergone both BCS and mastectomy. When the women were recruited to the study, the mean time since surgery was 168 days (SD = 518). Of the 10 patients who had already received RT, seven patients had breast

cancer in the collateral breast, while palliative RT for metastatic disease was planned for three patients.

Table 3 Demographic and Clinical Characteristics

Characteristics	Mean (SD)	Range
Age (years),	57.8 (9.2)	27-81
Baseline KPS	88.0 (11.0)	40-100
Baseline SCQ-19 score	3.3 (3.3)	0-18
Baseline total number of symptoms	9.4 (7.1)	0-32
	N	%
Education		
Primary and Secondary	116	65
College/University	63	35
Marital Status		
Married/living with partner	137	73
Unmarried/divorce/widow	50	27
Employment Status		
Employed	15	8
Not employed	167	92
Stage of disease		
Stage 0/DCIS	17	9
Stage I	70	39
Stage II	68	38
Stage III	25	14
Type of Surgery		
Breast conservative surgery	126	67
Mastectomy	68	36
Sentinel lymph node biopsy	140	75
Axillary lymph node dissection	95	51
Previous Treatment		
Hormonal therapy	5	3
Radiotherapy	10	5
Immunotherapy	5	3
Chemotherapy	86	46

Abbreviations: DCIS: Ductal Carcinoma In Situ, SCQ: Self-Administered Comorbidity Questionnaire, KPS: Karnofsky Performance Status Scale

4.2 Compliance

The overall dropout rate during the study period from baseline to six months (Time 5) was 16 % (n = 31) (Table 4). Most patients dropped out between the baseline measurement (Time 1) and 1 month (Time 2), which was approximately three weeks after the start of RT.

Each of the questionnaires had data missing for 0-10 % of the items, and the items missing were equally distributed among the questionnaires and over time. The items missing on each questionnaire on each measurement points are outlined in Table 4.

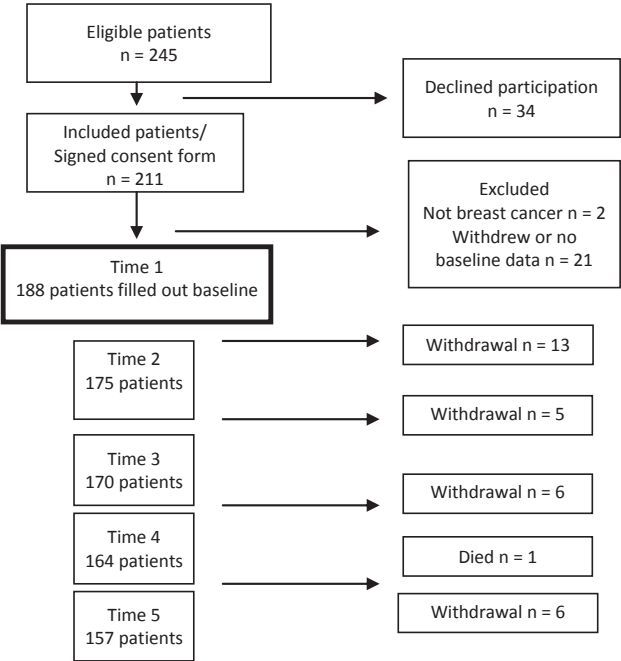


Figure 2 Flowchart of participants

Table 4 Compliance – Overall and for the specific questionnaires

	Time Point 1	Time Point 2	Time Point 3	Time Point 4	Time Point 5
Participants	188	175	170	164	157
SF-12	174	165	159	159	153
MSAS	183	175	170	164	157
SCQ-19	179	-	-	162	151
KPS	177	160	160	159	151

Abbreviations: SCQ: Self-Administered Comorbidity Questionnaire, SF-12: Short Form-12, KPS: Karnofsky Performance Status Scale, MSAS: Memorial Symptom Assessment Scale

4.3 Summary of papers – main results

The following pages summarize the main findings from each study (paper I-III) in the dissertation. Each paper describes the results in greater detail.

4.3.1 Paper I

Previous chemotherapy influences the symptom experience and quality of life of women with breast cancer prior to radiotherapy

The difference in symptom occurrence, severity, and distress of multiple symptoms between women with breast cancer who did and did not receive CTX prior to RT was analyzed in the first paper of this dissertation. Furthermore, the paper investigated the difference in QOL between women who did and did not receive CTX and the relationship between the various demographic and clinical characteristic and the total number of symptoms.

Women starting RT suffer from multiple symptoms (mean = 9.4, SD 7.1) and women who have received CTX prior to the start of RT have twice as many symptoms (mean = 12.6, SD 7.1) than women without CTX (mean = 6.5, SD 5.8). Previous CTX, a lower KPS score, and higher comorbidity profile were significant predictors for higher numbers of symptoms. More than 50 % of the total sample was experiencing lack of energy, worrying, difficulty sleeping, feeling drowsy, sweats and pain. Lack of energy, feeling drowsy, dry mouth and numbness/tingling had significantly higher occurrence rates for women who had received CTX, and were frequently reported (59 % – 79 %) in these women. No changes were found in the severity and distress score for the symptoms between the two treatment groups, except for the severity of hair loss, changes in skin, and difficulty swallowing. The latter symptoms had significantly higher severity scores among the women who had received CTX prior to RT. Women who had received CTX prior to RT also had a significantly lower SF-12 PCS before commencing RT, while the MCS scores were similar to those of the women who had received CTX. Compared with Norwegian normative data, the participants had significantly lower scores.

4.3.2 Paper II

Changes over time in occurrence, severity, and distress of common symptoms during and after radiotherapy for breast cancer

Changes over time in occurrence, severity, and distress of the six most prevalent symptoms at baseline (lack of energy, worrying, difficulty sleeping, feeling drowsy, sweats, and pain) were investigated during and after the course of RT in the second paper of the dissertation. In addition, the impact of five demographic and clinical characteristics (higher age, decreased functional status, higher number of comorbidities, ALND, and previous CTX) on the symptoms and the various dimensions was investigated.

The trajectory for the occurrence, severity, and distress for each symptom followed similar patterns through the study period (six months) for all symptoms investigated. Lack of energy, feeling drowsy and worrying changed in all three dimensions over time, while no changes was seen for the symptoms difficulty sleeping, sweats and pain.

Lack of energy increased significantly from baseline until two months (Time 3), and then decreased from two to six months (Time 5). All five covariates (higher age, decreased functional status, higher number of comorbidities, ALND, and previous CTX) increased the likelihood of reporting the symptom at baseline. However, for the patients who had received CTX and ALND, the likelihood of reporting lack of energy at baseline was much higher than for the women who had not previously received CTX or ALND. For the women who had received the treatment, the likelihood of reporting the symptom decreased steadily until six months. Similar patterns were also seen for the severity and distress of the symptom.

The women also reported a significant change in feeling drowsy over the six months. The likelihood of reporting feeling drowsy increased over the first month (Time 2), then decreased radically from month one to three (Time 2 to 3), and then decreased slowly from month three to six (Time 3 to 5). Having received CTX was the strongest predictor for change in the symptom. Women who received CTX had a

higher likelihood of reporting feeling drowsy at baseline, and had only a weak increase from baseline until 1 month. Women who had not received CTX had a radical increase in the likelihood of reporting the symptom from baseline until 1 month. Similar patterns were also seen for the severity and distress of the symptom.

The likelihood of reporting worrying was found to decrease from baseline until six months in the present study, for all three dimensions of the symptom. Younger women were more likely to report the symptom and to report higher severity and distress related to the symptom. A lower KPS score, higher comorbidity score, and having received CTX and ALND were also associated with a higher symptom burden.

The overall effect of the five covariates was increased symptom burden across all three dimensions.

4.3.3 Paper III

The relationships between demographic and clinical characteristics and quality of life during and after radiotherapy – in women with breast cancer

QOL was assessed using SF-12, before, during, and after the course of RT, and the risk factors for reduced QOL in women with breast cancer were identified.

The mean PCS did not change significantly ($p = 0.08$) during this period. However, the analyses identified three covariates as significant negative predictors ($p \leq 0.05$) of the PCS over the 6 months (i.e., higher comorbidity score, higher number of symptoms, and lower KPS score) after adjusting for statistically and clinically significant covariates. A higher number of symptoms and a higher comorbidity profile were negative predictors for the PCS level, while an increase in the KPS score was a positive predictor for a higher PCS during the six months of the study.

The MCS did not change between baseline and the 2-month assessment but the final model of the MCS revealed that four covariates were significant predictors of change in MCS in this period (i.e., CTX, higher number of symptoms, higher age, and education). A higher number of symptoms and higher age predicted worse MCS,

while having a college or university degree compared with a primary/secondary education and having undergone CTX was associated with an increase in MCS, for the first two months.

In the period from two to six months after the initiation of RT, MCS increased significantly. In the final model of the MCS for this period, two of the same and two different covariates were significant predictors of change (i.e., total number of symptoms, age, KPS, and time). A higher number of symptoms and higher age predicted worse MCS, while increased KPS and time since the start of RT predicted an increase in MCS.

In summary the MCS and PCS of QOL remained stable at a diminished level up until two months after inclusion. PCS remained stable while MCS improved. The total number of symptoms and age were significant predictors for change in both component scores (MCS and PCS) during the six months.

5.0 Discussion

The discussion part of this dissertation will be organized according to two main issues: the methodological issues of the study and the main results from the papers.

5.1 Methodological discussion

5.1.1 Design

A longitudinal design with repeated assessments in the same cohort was considered the most appropriate to meet the aims of the present study. We believe the time dimension is of importance for both the symptom experience and QOL. The original design was a one-year follow-up, to capture more of the longitudinal perspective after treatment, in order to differentiate chronic from acute symptoms after cancer treatment. The latter distinction is also important in planning symptom management strategies. When the longitudinal design was not allowed, the time points were selected to best capture the expected changes in the outcome measures over six months (i.e., symptoms and QOL). We were trying to capture maximum toxicity from RT from Time 2 and 3, while the longitudinal perspective as well as the effect of rehabilitation after RT was assessed at Time 4 and 5. We believe the longitudinal perspective was important to differentiate chronic from acute symptoms after cancer treatment and is further important for the development of more targeted symptom management strategies.

Having a control group of women with breast cancer who did not receive RT, enabling comparison of the symptom burden and QOL between women who did and did not receive RT, would increase the probability of identifying the symptoms that were directly associated with RT alone. However, this was not possible, because such a control group did not exist, and control groups are seldom used in cohort studies. As a substitute to having a control group, one alternative could have been to compare the results with age-matched data from the normal population. However, this was only done in paper I of the study. Paper III investigated QOL longitudinally during RT, and the results were therefore not compared with the normal population.

In addition, the use of the norm-based score of the SF-12 incorporates comparison against normal population in the scoring algorithm. The baseline data were used as controls for the longitudinal data. However, at baseline the women had already undergone several treatments (e.g., surgery, CTX, hormonal therapy), and the baseline measurement in our study is probably influenced by previous treatments. When analyzing the data we controlled for previous treatments, as some symptoms may be related to the previous treatment rather than to the RT in itself.

The longitudinal design strengthens the present study compared to a cross-sectional design with analyses of patient groups in different parts of the treatment and follow-up period. In cross-sectional design the ability to use the individual patients' baseline as a control is lost.

5.1.2 Patient recruitment, compliance and representativeness

Unfortunately, not all available patients were recruited into the study. The reasons for rejection are important when planning new studies, but REK does not allow systematic collection of this information, to protect the patient. Even though we did not ask the patients why they said no to participation, several patients spontaneously explained the reason, and the most common reason were that they did not have the energy to participate, or that they did not like questionnaires.

Since women with breast cancer had the simulation visit for radiation planning (the time of inclusion) only twice a week and they all met with a nurse on that day, we were able to invite all patients who met the inclusion criteria of the study to participate. For the patients who had agreed to participate but did not return the baseline questionnaire, a reminder letter was sent to their home address. To improve compliance for the recruited patients at baseline, help to fill out the questionnaires was offered, but most patients preferred to fill them out at home.

The patients could say no to receiving information about the study, but very few did that. This study had a participation rate of 76 %, which may be related to the time of inclusion (prior to RT). The women who declined participation may have felt exhausted from previous treatment and the disease in itself, or felt anxious for the

RT that they were about to commence. The participation rate is comparable to other studies investigating QOL (61;68;69;114).

However, the fact that nearly one out of four patients who met the inclusion criteria declined participation is of importance for the interpretation of the data. Some information about the non-participants was available. The patients who declined participation were significantly older ($p = 0.015$) than the study participants and were likely to be more exhausted from the disease and its treatment and might have had more comorbidities and poorer health than the participants did.

The 16% attrition rate during the follow-up was as expected, and was found to be comparable to other studies (66;68;114). As compliance is of major importance in longitudinal studies, different procedures for the follow-up period were implemented, to ensure best possible compliance. All eligible patients who were asked for participation were also given the phone number of the study nurse, so they could easily get help if they had any questions when filling out the questionnaires. For all time points, the questionnaires were sent by postal mail to the patients, including an explanatory letter and a prepaid return envelope. To improve compliance, the patients were allowed to bring the questionnaires to the hospital when they were there to receive treatment. Finally a reminder letter including a new questionnaire was sent for each time point, if we did not receive the new questionnaire within two weeks.

It is important to know which patients dropped out of the study, and if they differ from the ones that remain in the study. Previous studies have demonstrated that those who drop out differ from the participants in that they suffer more, and therefore they do not fill out questionnaires or they drop out of the study (114-116). Missing data should therefore be considered different from non-missing data. Still, dropout over time must be expected in longitudinal studies.

In the present study, the level of missing data was similar for all assessment points, and therefore we treated the data as missing at random (115;116). Patients who did not fill out the last questionnaires had a higher number of symptoms at the end of RT (Time 3) implying that the patients that dropped out might have been the ones who suffered the most. This is of importance when interpreting the data. The symptom burden and reduction in QOL might have been underestimated. As it is

difficult to avoid missing data in longitudinal clinical studies, it is important to select statistical methods that allow for incomplete data such as the mixed model analyses used for the longitudinal data in the present study.

The recruiting RT center treats women with breast cancer from a large geographical area based on the Norwegian Breast Cancer Group (NBCG) guidelines for RT (27). The results should therefore be generalizable to a larger population of women with breast cancer receiving postoperative RT. In addition, the sample is comparable with samples in other studies investigating symptoms and QOL for women receiving RT for breast cancer (40;64).

5.1.3 Psychometric properties of the instruments

We believe the content validity of the instruments used in the present study was satisfactory. For the SF-12, relevant segments of what defines QOL are included in the questionnaire (e.g., mental and physical). Both the SF-12 and the KPS are extensively used in research, and both have a well-known and satisfactory content validity. For the SCQ and MSAS, the number and nature of the symptoms and comorbidities were important for the choice of those instruments in the present study. We believe that the comprehensive list of cancer-specific symptoms made the MSAS relevant for the present study. The SCQ also had a comprehensive list with the most common diseases, including the opportunity to fill in three additional comorbidities, if they were not on the list.

A generic QOL questionnaire was used because the larger cohort study included patients with different cancer groups. A cancer-specific questionnaire could have been used, as all patients had a cancer diagnosis, but this would have made comparison across other diagnoses more difficult. A disadvantage of using a generic instrument is that it could be less sensitive for change for our study sample, as issues specific to breast cancer are not included in the questionnaire. A breast-cancer-specific questionnaire could have been added, to avoid the potential loss of information associated with the use of a less sensitive instrument. However, due to the already high number of questionnaires, a breast-cancer-specific questionnaire

was not added to the package in the present study. It was considered important not to give the patients too many questionnaires as they were in a vulnerable period of their lives.

Several strategies were used to ensure reliability in the present study. First, all the instruments (i.e., SF-12, KPS, SCQ, and the MSAS) that were used in the present study are well-known and have been used extensively in previous trials with satisfactory reliability (36;57;72;73;78). All Norwegian versions of the inventories have also been used previously, except for the MSAS, which was translated as part of this study using recommended guidelines (89). A pilot test of the questionnaires was conducted, to ensure appropriate layout, to test the combination of several different inventories, and to test the Norwegian version of the MSAS. Finally, the strategy for reducing random errors in the database was to double-check all data from the electronic database against hard copies. When errors were detected, all questionnaires for all five time points were double-checked and corrected against the hard copies, to ensure that no errors were introduced.

Cronbach's alpha is the most commonly test for internal consistency, and as described previously, Cronbach's alpha is not commonly used for the instruments used in the present study (SF-12, MSAS, KPS, SCQ). Cronbach's alpha was not used for the MSAS, SCQ or KPS in the present study because we did not expect internal consistency in a list of symptoms or comorbidities. Further, it is not possible to run Cronbach's alpha for the KPS, because patients only tick one box, and internal consistency can therefore not be measured. The creation of the two component scores for the SF-12 is based on different weights, and the value of doing a Cronbach's alpha test is therefore debated. A test-retest is an alternative test for internal consistency. This was not conducted in the present study, as the time interval was not appropriate, and change was expected due to treatment. Still, a test-retest situation could have been part of the pilot study if more patients had been included and had agreed to fill out some of the questionnaires twice. Another alternative could have been to ask a group of the included patients to fill out some of the instruments one extra time, with the purpose of testing the reliability. Despite of the lack of reliability testing in the present study, the instruments used all have well-

established reliability, and have all been previously used in cancer populations (48;74;75;79;80;85;87;94).

5.1.4 Memorial Symptom Assessment Scale (MSAS)

The MSAS captures the complexity of symptoms by including the multidimensional aspects of each of them (e.g., occurrence, frequency, severity, distress). This is an essential feature in the choice of symptom inventories. However, even though the 32 symptoms could be regarded as typically cancer-related, the instructions for the instrument do not specify that only symptoms related to the cancer diagnosis or its treatment should be reported. Patients have therefore reported all symptoms they experienced, and not only cancer-related symptoms. This introduced a potential bias to the dataset, as the intention of the study was to describe symptoms related to the cancer diagnosis or its treatment. However, we believe that in the investigation of changes in symptoms during cancer treatment, ‘chronic’ symptoms remained more stable, and we were therefore able to capture the changes in important cancer-related symptoms. Further, the comorbidity variable was used in the interpretation of the symptom data at baseline, to control for this potential bias.

The layout of the MSAS has some limitations, because the lines are narrow and there are massive amounts of text. To correct for this limitation, if patients had indicated the frequency, severity or distress of a symptom they ‘did not have’, we coded the response as if the patient had the symptom; see appendix. When treating the data as described, we detected missing data for 5-10 % of items during the study period for the MSAS.

When creating the variable ‘total number of symptoms’ we had a liberal approach when summarizing the number of symptoms for each patient. If the patient had only described one symptom on the MSAS, the total number of symptoms was coded as one. We believe this approach was appropriate for interpreting the data in the present study, without compromising the validity. The frequency dimension was not used in our data analyses due to the already high number of variables, and the fact that the severity and distress dimensions already captured important aspects of the symptom experience.

5.1.5 Short Form 12 (SF – 12)

Even though the SF-12 is empirically developed (90), the instrument includes eight dimensions (i.e., physical functioning, role-physical, bodily pain, general mental health, vitality, social functioning, role-emotional, mental health) that are usually part of the concept of health related quality of life and reflect the QOL definitions of Ferrans (1990) as well (55).

The fact that the questionnaire is a generic QOL questionnaire makes it easier to compare results across diagnoses, which was an important aspect for the main study. However, due to the lack of disease-specific aspects of QOL, the sensitivity to changes over time might have been reduced. Some controversies exist regarding the assumption of non-correlation between the MCS and PCS (117-119) in the scoring manual of the SF-12. The opponents of the original scoring manual state that MCS and PCS cannot be separated, as the dimensions are correlated in the real world, and that the current scoring algorithm may lead to opposite levels in the extreme values (117;119-121). The developers of the instrument argue for the choice of orthogonal factor rotations, as a way to avoid double loading of scores on both dimensions, and still maintain the highest amount of variance in each scale (92). We have reflected on this potential problem for our data, and believe that the possible bias imposed by the use of orthogonal factor rotations is fairly stable, and that our longitudinal data on changes over time will not be compromised due to the assumption of uncorrelated sum scores.

5.1.6 Self-Administered Comorbidity Questionnaire (SCQ – 19)

The self-reported questionnaire for comorbidities (SCQ-19) was selected rather than collecting the information from the medical records, as research has shown that patients can accurately assess their medical condition (78). The patients had the opportunity to add three additional comorbidities, which reduced the chance of

leaving out any conditions. Another advantage of the SCQ-19 was that it allowed the women to describe the severity and the impact of their comorbidities (78).

As certain comorbid conditions typically do not limit a person's overall function, while others may impose severe functional limitations, we believed a sum score most accurately describes the burden of comorbidities.

5.1.7 Data analyses

The dissertation presents results from analyses on both cross-sectional and longitudinal data. For the longitudinal data, the end points (i.e., symptoms and QOL) were measured with both categorical (i.e., occurrence, severity, distress of symptoms) and continuous data (i.e., QOL and total number of symptoms), therefore different analytic approaches were used. All data analyses have been conducted with close collaboration with statisticians to ensure best possible quality. Due to the high number of variables in paper I, correction for multiple testing was considered appropriate. In papers II and III, only a small number of variables were investigated, and it made more sense to evaluate each predictor on its own. Correction for multiple testing was therefore not conducted (122).

An important reason for using mixed-model analyses in the present study is that they allow for incomplete data sets, as will always be the case in longitudinal designs, also for the present study. This means that all the available data are used, which also increases the generalizability of the study, as the results are based on all participants in the study, and not only those with complete data.

5.1.8 Theory of Unpleasant Symptoms

At the start of the study, the Theory of Symptom Management (TSM) was used. However, based on our research questions, and the focus on the multidimensional aspect of the symptoms and their predictors, the TOUS was used for the last two papers and for the analyses and interpretation of the data in the dissertation. The TOUS has been a helpful tool in identifying the elements of the individual symptoms,

understanding the interactions among symptoms, and distinguishing the different influencing factors of a symptom. Furthermore, the model has been of great importance in planning of the statistical analyses that investigated covariates of the symptom burden.

In the model, the influencing factors are described as influencing each other as well as the symptoms. In our study, this means that the experience of receiving RT (physiological factor) is influenced by both situational factors (e.g., personal relationships) and psychological factors. Similar situational factors may have different impacts on the symptom experience as well as on the other situational factors. They must therefore be described on an individual level, as in the present study. For instance, personal relationships can be an asset (e.g., social network, partnership) or something that increases the negative experience of a symptom (e.g., lack of social network, loneliness).

The TOUS has been helpful in understanding the interaction of those factors and its importance for the symptom experience. In symptom research, it is therefore essential to include the situational factors in the data collection, as we did in the present study. The TOUS further describes how the symptoms and the various dimensions are influenced by these three factors. Despite the fact that the figure does not include arrows between the various dimensions of the symptoms, the model acknowledges that the dimensions are related to each other (Figure 1).

In the present study, QOL was used as an outcome measure for performance outcome. The feedback effect of QOL on the symptoms and the situational factors was not investigated in the present study, even though we acknowledge that according to the model, the symptom experience is a continuous process, and QOL has a feedback effect on both the symptoms and the situation factors. However, investigating those relationships was not part of our research questions.

5.2 Main results

The discussion about the results from this study will be organized according to the main findings.

5.2.1 High symptom burden before radiotherapy

A recent study by Deshields et al. (2014) (123) also used the MSAS to investigate the persistence of symptom burden across one year in a heterogeneous (i.e., breast, colorectal, gynecological, lung, and prostate cancer) sample of cancer patients. The women with breast cancer from the latter study reported an average of 11.2 symptoms (SD 8.1) at baseline, while the average number in the present study at baseline was 9.4 (SD 7.1). However the amount of treatment the patients had received at baseline was not similar for the two studies.

Of the six most prevalent symptoms before starting RT (lack of energy, worrying, difficulty sleeping, feeling drowsy, sweats, and pain), only difficulty sleeping was also reported as one of the most severe and distressful symptoms (paper I). On the other hand, 'hair loss' was described as the most severe symptom, while 'problems with sexual interest' was described as the most distressing symptom before starting RT (paper I). These findings highlight the challenge of symptom management: should the interventions be targeted toward diminishing the severity or the distress of the symptoms? In the original paper by Portenoy et al. (36) the correlation between severity and distress of the symptoms is described as high ($r = 0.70$), and reducing the experience of one of the dimensions might therefore reduce the other dimensions as well. For some symptoms, reducing the severity is impossible (e.g., hair loss); however, learning coping strategies to reduce the distress of the experience might be possible. This in turn highlights the need for symptom management strategies that target the specific dimensions of the symptoms directly. Strategies for reducing the severity of a symptom would probably be targeted towards reducing its strength (e.g., pain); however, the various symptoms would need different strategies. The distress dimensions according to the TOUS (23), describe the degree to which an individual is bothered with the symptom, and the

significance that the individual attaches to the symptom. Therefore, the symptom management strategies targeting the distress dimension would be more individual. In the theory of Symptom Management (70) the strategies are described as preventing, delaying or minimizing the symptom experience. This is further described as effective in three ways: by reducing frequency of the symptom experience, by minimizing the severity of the symptom, or by relieving the distress associated with the symptom. The theory highlights the increased attention given to self-management strategies used by the patients, thus shifting the responsibility of managing symptoms to the individual patient. Intervention studies using such strategies are warranted.

Recent evidence suggests that the burden of experiencing multiple symptoms is higher than the sum of the actual number of symptoms (124;125), since one symptom may cause other symptoms, or a symptom may be perceived as worse when it occurs simultaneously with other symptoms. Therefore, describing multiple symptoms is necessary to understand which symptoms occur concurrently, and to understand the total symptom burden.

The present study adds further knowledge to the literature on the experience of multiple symptoms for women starting RT for breast cancer, in describing the high symptom burden these women are experiencing and the complexity of the symptom dimensions. Further, the present study highlights the importance of multidimensional symptom assessment to capture the symptom burden, and to target individual and adequate symptom management strategies.

5.2.2 Similar pattern for the trajectory of occurrence, severity and distress

When changes in the different dimensions of the most frequently occurring symptoms during the course of RT were investigated, surprisingly, similar patterns were found for the three dimensions (i.e., occurrence, severity, and distress) of the most common symptoms during RT. We believe there are different possible explanations for this finding. One is that the results accurately describe the nature of those specific symptoms for women receiving RT for breast cancer, and that the

trajectories would differ if other and more rarely reported symptoms had been investigated. Another possible explanation is that severity and distress dimensions are, as described by Portenoy et al. (1994,) highly correlated phenomena and typically follow similar trajectories. The findings of similar patterns in the three dimensions (i.e., occurrence, severity, distress) are still unique, as we have not been able to find any other studies that have investigated several dimensions of the most common symptoms longitudinally for women receiving RT for breast cancer.

According to TOUTS, there are important theoretical differences between the dimensions of a symptom, and the theory describes severity and distress as distinct but related dimensions of a symptom (23). The theory further recognizes the similarities of the dimensions, supporting Portenoy et al. (1994) who described the dimensions as highly correlated phenomena (36). On the other hand, the theory also describes the distinct differences between the two dimensions; where severity refers to the strength of a symptom while distress reflects the degree to which a patient is bothered by a symptom (23). The importance of the different dimensions of a symptom would probably vary between patients, based on their previous experience with the symptom and how the symptoms influence their lives. The symptom experience is likely to differ both between symptoms and between patients. Further research is needed in this area.

The present study presents unique and new findings regarding the trajectory of the different dimensions for the most common symptoms during RT for women with breast cancer. The findings warrant replication in future research, where other and rarer symptoms should be investigated longitudinally, to see if they follow the same patterns for the different dimensions.

5.2.3 The importance of chemotherapy on symptoms and quality of life

One of the main findings from this study is the negative impact of CTX on both the symptom experience and QOL both at baseline and over time. We also found CTX to be negatively related to the mental health dimension of QOL.

The symptoms with significantly different occurrence rates between women who did and did not receive CTX prior to RT were mostly symptoms that Portenoy et al. (1994) described as physical symptoms (e.g., lack of energy, pain, dry mouth, numbness/tingling, I don't look like myself, nausea, hair loss, constipation, shortness of breath, food tastes different, lack of appetite, swelling of arms and legs, diarrhea, mouth sores, changes in skin, problems with urination) (36). Surprisingly, the symptoms described as psychological (e.g., worrying, feeling nervous, difficulty sleeping, feeling irritable, difficulty concentrating) were not found to differ between the two groups at baseline (prior RT) even though the CTX patients had a more advanced stage of disease (paper I). The lack of differences in the psychological symptoms before start of RT may be explained by the different time since diagnosis. Patients who had received CTX had more time to cope with the diagnosis and its treatment. This finding may indicate that there is no clear relationship between a high number of physical symptoms and psychological distress. However, no conclusions can be drawn from the present study, only presenting cross-sectional data, as more sophisticated statistical analyses should be used to further investigate the relationship between a high number of symptoms and psychological distress. Still, the importance of addressing psychological distress in women with breast cancer has been established in a recent study (126) where women with breast cancer were screened for psychological distress using an emotion thermometer. They found that the women experienced a high degree of distress or anxiety. This is also consistent with some previous reports (127-130).

Interestingly, in paper I, we did not find that CTX increased the severity or distress of any of the MSAS symptoms at baseline except for three symptoms (hair loss, changes in skin, difficulty swallowing). This may suggest that having several symptoms does not necessarily increase the severity and distress of other symptoms. No other studies compared the severity and distress scores for symptoms experienced by women with breast cancer, based on CTX. However, investigation of the six most frequently occurring symptoms with more sophisticated analyses longitudinally and corrected for confounders (paper II) showed that CTX actually increased the likelihood of reporting higher severity and distress scores for some of the symptoms both at baseline and over time (e.g., worrying, feeling drowsy, lack of

energy). This highlights the importance of the use of longitudinal data, and more advanced statistical analyses, as a way to utilize the data in the most accurate way, and to reduce potential bias.

The occurrence rate for worrying reported in paper I was not significantly different at baseline between patients who had and had not received CTX. However, when we investigated worrying using mixed model analyses (paper II) and adjusted for the impact of other covariates, CTX was found to increase the likelihood of reporting worrying at baseline, including the likelihood of reporting a higher severity and distress score. The different results regarding the impact of CTX on worrying (paper I and II) are likely to be due to the use of descriptive statistics, in contrast to mixed model analyses.

CTX was also found to be a significant predictor for the total number of symptoms prior to RT (paper I), as well as longitudinally (paper II) for some symptoms (worrying, difficulty sleeping, feeling drowsy). Still CTX, was not found to be negatively related to the PCS of QOL, when corrected for confounders (paper III). The fact that a higher number of symptoms was found to be related to reduced QOL (both PCS and MCS), and not to CTX, may indicate that it is not the CTX in itself that is of importance for QOL, but the symptoms following CTX that lead to diminished QOL. This finding requires attention when planning for appropriate interventions or management strategies for improving QOL for women receiving RT for breast cancer.

This study only investigated predictors of the total number of symptoms at baseline (prior to RT) and not longitudinally. However, significant differences in the total number of symptoms between the group of women who had and had not received CTX were also found after six months in the present study (data not shown), and may indicate the prolonged effect CTX has on the symptom experience for these women.

The present study highlights the huge impact CTX has for women with breast cancer, prior to, during and after the course of RT, by increasing the symptom burden for these women which again leads to diminished QOL.

5.2.4 Minimal change in quality of life during the course of radiotherapy

One of the main findings reported in paper III was the minimal change in QOL during RT. This is in line with previous reports of QOL during the course of RT (59;60;62;65;131). One concern could be that the SF-12 is not sensitive to changes in QOL for these women during RT, and that a breast-cancer-specific tool could have captured a change. On the other hand, other reports investigating QOL during RT for women with breast cancer using a disease-specific QOL inventory (e.g., EORTC) (59;60;62;65), still found no changes in QOL during RT. We found PCS to be stable at a diminished level through all six months, below the average for the normal population, and PCS did not deteriorate additionally during RT. The total number of symptoms was highly related to poorer levels of both MCS and PCS, and the findings were consistent with some other reports (20;48;82;123). In the present study, the PCS remained at the same level, although the total number of symptoms decreased after six months. Other covariates are also important for explaining changes in PCS, and physical health captures more than the effects of symptoms. The MCS score, on the other hand, was found to be higher and to improve significantly during the study period in the present study compared to the PCS.

A consensus on the long term effect on QOL for breast cancer survivors was found in the literature across early (133) and late studies (133); no major differences between breast cancer survivors and healthy controls have been detected, except that cancer survivors report more physical symptoms (134). In summary, the present study demonstrated that a reduction in the symptom burden after six months did not lead to increased PCS, and that PCS remained at a diminished level of QOL before, during and after RT. In contrast, the MCS increased despite a consistently high level of symptoms.

6.0 Main conclusions

In this dissertation, symptoms and QOL for women receiving RT for breast cancer have been investigated. The main findings can be summarized as follows.

- Women with breast cancer starting RT experience a high number of symptoms
- The most frequent symptoms do not always cause the most distress
- Women who have received CTX have twice as many symptoms as women who have not received CTX when starting RT
- Having received CTX was found to be one of the most significant predictors for reporting a higher number of symptoms during RT
- Symptoms most frequently reported followed similar trajectories for the occurrence, severity and distress of the symptoms during the course of RT
- Having received CTX was the strongest predictor for the occurrence, severity and distress of the most commonly reported symptoms over time
- QOL remained at a diminished level during the course of RT, except for mental health, which increased at the end of RT
- A higher number of symptoms is highly associated with a lower QOL score

6.1 Implications for clinical practice

These findings have important implications for clinical practice. First of all, multidimensional symptom assessment should be a part of the clinical routines for women starting RT for breast cancer. Patients should be asked to fill out a comprehensive symptom inventory (including various dimensions of the symptoms) before starting RT or other treatment. There are several different strategies to facilitate this, and the symptom inventories can also be completed electronically from home. However, assessing the symptoms without introducing symptom management strategies does not help the patients who are experiencing them. Therefore, symptom management strategies must be introduced to the patients in an early phase of the treatment process, and must be targeted to the different dimensions of the symptoms reported. Patients receiving CTX must be prepared for physical symptoms that follow the treatment and the trajectory of symptoms during the course of RT, and its possible effect on QOL.

The predicting factors for a high symptom burden or the most frequently reported symptoms (i.e., worrying, difficulty sleeping, feeling drowsy, lack of energy, pain, sweats), should be used by health care providers to provide more personalized symptom management strategies for women with breast cancer during RT. Different symptoms require different symptom management strategies, and one cannot expect all symptoms to be eliminated. Still, management strategies should focus on how to reduce the symptom experience to a minimum and to help patients to cope with the symptoms they experience.

6.2 Future research

This dissertation has discussed the multiple dimensions of symptoms, the high symptom burden and its predictors, and changes over time in both symptoms and QOL during the course of RT for women with breast cancer. Future research should be divided into two segments: descriptive and experimental research. The descriptive research should focus on commonly used symptom management strategies, as there is little literature on this topic. Descriptive longitudinal studies

should also be used to get a deeper understanding of the synergistic effects some symptoms have on each other. The TOUS should be used in the planning process of such a study, to ensure that all interactions and feedback effects of the symptom experience are captured. However, and more importantly, experimental design should be used to evaluate appropriate interventions to manage different dimensions of frequently reported symptoms for women with breast cancer who are receiving RT. A control group receiving 'standard symptom management strategies' should be used as part of an intervention study, to test the effect of the interventions. Finally, a qualitative approach should also be used in future research to obtain more in-depth knowledge on the patient experience regarding symptom management strategies.

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Kreftklinikken
RADIUMHOSPITALET

2008 Cluster Studien

**”Symptomer hos kreftpasienter
i behandling”**

Spørreskjemaer til pasienter



Draft

Reg. nr.:

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Initialer:

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DATO FOR UTFYLING:

		.			.				
dag			måned			år			

BAKGRUNNSOPPLYSNINGER

Vennligst fyll inn eller sett kryss ved det som passer

1. Kjønn

- ☐ Mann
☐ Kvinne

2. Hvilket år er du født?

		.			.				
dag			måned			år			

3. Hva er din sivilstatus?

- ☐ Ugift
☐ Gift / samboer
☐ Skilt
☐ Enke / enkemann

4. Hvordan bor du?

- ☐ Bor alene
☐ Bor sammen med noen

5. Hvor mange barn har du daglig omsorg for?

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 antall barn

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6. Hvilken utdanning er den høyeste du har fullført?*(sett bare ett kryss)*

- ☐ Grunnskole 7-10 år (framhaldsskole)
- ☐ Ett- eller toårig videregående skole, yrkesskole, real- eller middelskole
- ☐ Artium, økonomisk gymnas, 3-årig videregående skole
- ☐ Universitet og/eller høyskole opptil 4 år
- ☐ Universitet og/eller høyskole mer enn 4 år
- ☐ Hvis annet, spesifiser, inkl. hvor mange år

--

7. Er du i arbeid utenfor huset for tiden?*(sett bare ett kryss)*

- ☐ Ja, heltidsarbeid
- ☐ Ja, deltidsarbeid
- ☐ Sykemeldt (helt eller delvis)
- ☐ Uføretrygdet
- ☐ Alderspensjonert
- ☐ Arbeidsledig
- ☐ Hvis annet, spesifiser

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TILLEGGSSYKDOMMER (SCQ-18)

Det følgende er en liste over vanlige medisinske problemer.

Sett ett kryss for hvert problem om hvorvidt du har problemet nå (ja eller nei).

Hvis du HAR problemet, så svar på spørsmålene om behandling og aktiviteter til høyre. Hvis du IKKE HAR problemet, gå videre til neste problem.

Problem	Har du problemet?	HVIS JA: Får du behandling for det?	HVIS JA: Begrenser det dine aktiviteter?
1. Hjertesykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
2. Høyt blodtrykk	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
3. Lungesykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
4. Diabetes	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
5. Magesår / magesykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
6. Tarmsykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
7. Nyresykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
8. Leversykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
9. Anemi eller annen blodsykdom	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
10. Hodepine	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
11. Depresjon	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
12. Slitasjegikt / artrose	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
13. Rygg / nakkesmerter	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
14. Leddgikt / revmatoid artritt	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
15. Sykdom i bindevev eller muskulatur	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
16. Hudlidelser	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
17. Andre medisinske problemer (angi)	<input type="text"/>	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
	<input type="text"/>	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei
	<input type="text"/>	<input type="checkbox"/> Ja <input type="checkbox"/> Nei	<input type="checkbox"/> Ja <input type="checkbox"/> Nei

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FUNKSJONSTILSTAND (KARNOFSKY)

Sett ett kryss i den ruten som passer best.

- 100 ☐ Normal, ingen plager eller subjektive tegn på sykdom
- 90 ☐ Klarer normal aktivitet, sykdommen gir lite symptomer
- 80 ☐ Klarer med nød normal aktivitet. Sykdommen gir en del symptomer
- 70 ☐ Klarer meg selv, ute av stand til normal aktivitet eller aktivt arbeide
- 60 ☐ Trenger noe assistanse, men klarer stort sett å tilfredsstille egne behov
- 50 ☐ Trenger betydelig hjelp og stadig medisinsk omsorg
- 40 ☐ Ufør, trenger spesiell hjelp og omsorg



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SYMPTOMLISTE (MSAS)

Veiledning: Vi har listet opp 32 symptomer nedenfor. Les hvert av dem nøye. Hvis du har hatt symptomet i løpet av siste uken, la oss få vite hvor ofte du hadde det, hvor kraftig det var det meste av tiden, og hvor mye det plaget eller bekymret deg, ved å sette ett kryss i den ruten du synes passer best. Hvis du IKKE HAR HATT symptomet, sett ett kryss i den ruten merket HAR IKKE HATT symptomet.

I løpet av den siste uken: Har du hatt noen av de følgende symptomene?	Har ikke hatt symptomet	Hvis JA: Hvor ofte hadde du symptomet?					Hvis JA: Hvor kraftig var symptomet, det meste av tiden?				Hvis JA: Hvor mye plaget eller bekymret symptomet deg?					
		Sjelden	Av og til	Ofte	Nesten hele tiden		Svakt	Moderat	Kraftig	Svært kraftig		Ikke i det hele tatt	Litt	En del	Ganske mye	Svært mye
Vanskelig å konsentrere seg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smerter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Har lite energi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hoste	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Føler meg nervøs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tørr i munnen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kvalme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Søvnig, mye trøtt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nummen / prikker i hender / føtter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Søvnvansker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Luft i magen / oppblåst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problemer med vannlating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kaster opp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kortpustet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diaré	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Føler meg trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Svette	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bekymrer meg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problemer med seksuallyst / aktivitet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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SYMPTOMLISTE (MSAS) - del 2

I løpet av den siste uken: Har du hatt noen av de følgende symptomene?	Har ikke hatt symptomet	Hvis JA: Hvor ofte hadde du symptomet?					Hvis JA: Hvor kraftig var symptomet, det meste av tiden?				Hvis JA: Hvor mye plaget eller bekymret symptomet deg?				
		Sjelden	Av og til	Ofte	Nesten hele tiden	Svakt	Moderat	Kraftig	Svært kraftig	Svært mye	Ganske mye	En del	Litt	Ikke i det hele tatt	
Kløe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Manglende matlyst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Svimmel / ør	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Vanskelig å svelge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Føler meg irritabel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Sår i munnen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Maten smaker annerledes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Vekttap	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Mistet håret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Treg mage / forstoppelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hoven i armer og ben	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
"Jeg ser ikke ut som meg selv lengre"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Forandringer i huden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hvis du har hatt noen andre symptomer i løpet av den siste uken, vennligst skriv de opp nedenfor, og angi hvor mye det plaget eller bekymret deg.										Svært mye	Ganske mye	En del	Litt	Ikke i det hele tatt	
Annet: <input style="width: 550px; height: 25px;" type="text"/>										<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Annet: <input style="width: 550px; height: 25px;" type="text"/>										<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Annet: <input style="width: 550px; height: 25px;" type="text"/>										<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	



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SMERTER (BPI)

1. Gjennom livet har de fleste av oss hatt smerter (som lett hodepine, forstuelser eller tannpine).

Har du i dag smerter av et annet slag enn slike dagligdagse smerter?

☐ Ja ☐ Nei

Hvis NEI, gå til side 10

2. Vil du skravere de områdene på kroppen hvor du har smerter. Marker med et kryss der du har mest vondt.

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D. Wilkie and K. Pontillo

Ikke fyll ut rutene (fylles ut av studiegruppen)

mest vondt

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3. Vennligst sett ett kryss i den ruten som best beskriver de sterkeste smertene du har hatt i løpet av de siste 24 timer.

Ingen smerter	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige smerter
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

4. Vennligst sett ett kryss i den ruten som best beskriver de svakeste smertene du har hatt i løpet av de siste 24 timer.

Ingen smerter	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige smerter
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

5. Vennligst sett ett kryss i den ruten som best angir hvor sterke smerter du har i gjennomsnitt.

Ingen smerter	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige smerter
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

6. Vennligst sett ett kryss i den ruten som best angir hvor sterke smerter du har akkurat nå.

Ingen smerter	0	1	2	3	4	5	6	7	8	9	10	Verst tenkelige smerter
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

7. Hvilken behandling eller medisiner får du for å lindre smertene dine?

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8. I hvor stor grad har behandling eller medisiner lindret smertene dine de siste 24 timene? Vennligst sett ett kryss i den ruten med prosenttallet som viser hvor stor smertelindring du har fått.

Ingen lindring	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%	Fullstendig lindring
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Sett ett kryss i den ruten som for de siste 24 timene best beskriver hvor mye smertene har virket inn på:

9. Daglig aktivitet

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket

10. Humør

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket

11. Evne til å gå

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket

12. Vanlig arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket

13. Forhold til andre mennesker

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket

14. Søvn

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket

15. Livsglede

	0	1	2	3	4	5	6	7	8	9	10	
Ikke påvirket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fullstendig påvirket



Draft

Reg. nr.:

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SPØRRESKJEMA OM HELSE (SF-12)

INTRODUKSJON: Dette spørreskjemaet handler om hvordan du ser på din egen helse. Disse opplysningene vil hjelpe oss til å få vite hvordan du har det og hvordan du er i stand til å utføre dine daglige gjøremål.

Hvert spørsmål skal besvares ved å sette ett kryss (X) i den ruten som passer best for deg. Hvis du er usikker på hva du vil svare, vennligst svar så godt du kan.

1. Stort sett vil du si at din helse er:

- ☐ Utmerket ☐ Meget god ☐ God ☐ Nokså god ☐ Dårlig

De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig uke. Er din helse slik at den begrenser deg i utførelsen av disse aktivitetene nå? Hvis ja, hvor mye?

- | | Ja, begrenser
meg mye | Ja, begrenser
meg litt | Nei, begrenser
meg ikke i det
hele tatt |
|---|--------------------------|---------------------------|---|
| 2. Moderate aktiviteter som å flytte et bord, støvsuge, gå en tur eller drive med hagearbeid | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Gå opp trappen flere etasjer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

I løpet av den siste uken, har du hatt noen av de følgende problemer i ditt arbeid eller i andre av dine daglige gjøremål på grunn av din fysiske helse?

- | | Ja | Nei |
|--|--------------------------|--------------------------|
| 4. Du har <u>utrettet mindre</u> enn du hadde ønsket | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Du har vært hindret i å utføre visse typer arbeid eller gjøremål | <input type="checkbox"/> | <input type="checkbox"/> |

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I løpet av de siste 4 ukene, har du hatt noen av de følgende problemer i ditt arbeid eller andre av dine daglige gjøremål på grunn av følelsesmessige problemer (som for eksempel å være depriment eller engstelig)?

	Ja	Nei
6. Du har <u>utrettet mindre</u> enn du hadde ønsket	<input type="checkbox"/>	<input type="checkbox"/>

7. Du har utført arbeidet eller andre gjøremål mindre <u>grundig</u> enn vanlig	<input type="checkbox"/>	<input type="checkbox"/>
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8. I løpet av de siste 4 ukene, hvor mye har smerter påvirket ditt vanlige arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)?

☐ Ikke i det hele tatt ☐ Litt ☐ En del ☐ Mye ☐ Svært mye

De neste spørsmålene handler om hvordan du har følt deg og hvordan du har hatt det de siste 4 ukene. For hvert spørsmål, vennligst velg det svaralternativet som best beskriver hvordan du har hatt det. Hvor ofte i løpet av de siste 4 ukene har du:

	Hele tiden	Nesten hele tiden	Mye av tiden	En del av tiden	Litt av tiden	Ikke i det hele tatt
9. Følt deg rolig og harmonisk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Hatt mye overskudd	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Følt deg nederfor og trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. I løpet av de siste 4 ukene, hvor mye av tiden har din fysiske helse eller følelsesmessige problemer påvirket din sosiale omgang (som det å besøke venner, slektninger osv.)?

☐ Hele tiden ☐ Nesten hele tiden ☐ En del av tiden ☐ Litt av tiden ☐ Ikke i det hele tatt

SØVNPROBLEMER (GSDS)

Tenk tilbake på den siste uken. Hvor mange dager har du: (sett ett kryss i den aktuelle ruten)

	Aldri							Hver dag
1. Hatt problemer med å sovne	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
2. Våknet i løpet av søvnperioden	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
3. Våknet for tidlig og fikk ikke til å sovne igjen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
4. Følt deg uthvilt når du våkner på slutten av en søvnperiode	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
5. Sovet dårlig	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
6. Følt deg søvnig i løpet av dagen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
7. Kjempet for å holde deg våken gjennom dagen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
8. Følt deg irritabel i løpet av dagen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
9. Følt deg trøtt eller utmattet i løpet av dagen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
10. Følt deg tilfreds med søvnkvaliteten	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
11. Følt deg våken og energisk gjennom dagen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
12. Fått for mye søvn	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
13. Fått for lite søvn	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
14. Tatt en blund til planlagt tid	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
15. Sovnet uten at det var planlagt	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
16. Drukket alkohol for å få til å sovne	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
17. Brukt tobakk for å få til å sovne	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
18. Brukt andre stimuli for å sovne (f.eks: avslapping, musikk, lesing)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
19. Brukt naturmedisinske midler for å sovne	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
20. Brukt reseptbelagt sovemedisin for å få til å sovne	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>
21. Brukt Paracet eller annet smertestillende for å sove	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	6 <input type="checkbox"/>	7 <input type="checkbox"/>

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DEPRESJON (CES-D)

Vennligst sett ett kryss i den ruten som markerer hvor ofte du har følt det slik i løpet av den siste uken.

	Aldri eller nesten aldri (Mindre enn 1 dag i uken)	Litt av tiden (1-2 dager i uken)	En del av tiden (3-4 dager i uken)	Hele eller nesten hele tiden (5-7 dager i uken)
1. Jeg var plaget av ting som vanligvis ikke plager meg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Jeg hadde dårlig appetitt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Jeg var nedstemt og kunne ikke riste det av meg, til tross for støtte fra familie og venner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Jeg følte meg like mye verdt som andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Jeg hadde problemer med å konsentrere meg om det jeg holdt på med	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Jeg følte meg depriment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Jeg følte at alt var et ork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Jeg så lyst på framtiden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Jeg tenkte at livet mitt hadde vært mislykket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Jeg følte meg engstelig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Jeg sov urolig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Jeg følte meg lykkelig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Jeg var mer taus enn vanlig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Jeg følte meg ensom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Folk var uvennlige	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Jeg satte pris på livet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Jeg gråt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Jeg følte meg trist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Jeg følte at folk mislikte meg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Jeg var initiativløs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Draft

Reg. nr.:

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TRETTTHET (LFS)

Vi ønsker å vite mer om energinivået ditt.
Nedenfor er det 18 utsagn vi ber deg svare på.

INSTRUKSJONER: For hvert utsagn nedenfor -
Sett ett kryss i den ruten som best indikerer hvordan du føler deg akkurat nå.

1.	Ikke sliten i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært sliten
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2.	Ikke trøtt i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært trøtt
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3.	Ikke døsig i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært døsig
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4.	Ikke utmattet i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært utmattet
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5.	Ikke utslitt i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært utslitt
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6.	Ikke energisk i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært energisk
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7.	Ikke aktiv i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært aktiv
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8.	Ikke sprek i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært sprek
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9.	Ikke effektiv i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært effektiv
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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10.

Ikke livlig i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært livlig
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

11.

Ikke utkjørt i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært utkjørt
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

12.

Ikke utslått i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært utslått
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

13.

Å holde øynene åpne er ikke anstrengende i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Å holde øynene åpne er veldig anstrengende
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

14.

Å bevege kroppen er ikke anstrengende i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Å bevege kroppen er veldig anstrengende
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

15.

Å konsentrere seg er ikke anstrengende i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Å konsentrere seg er veldig anstrengende
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

16.

Å holde i gang en samtale er ikke anstrengende i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Å holde i gang en samtale er veldig anstrengende
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

17.

Jeg har absolutt ikke noe behov for å lukke øynene	0	1	2	3	4	5	6	7	8	9	10	Jeg har et veldig sterkt behov for å lukke øynene
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

18.

Jeg har absolutt ikke noe behov for å legge meg nedpå	0	1	2	3	4	5	6	7	8	9	10	Jeg har et veldig sterkt behov for å legge meg nedpå
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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Reg. nr.:

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LIVSKVALITETS SPØRRESKJEMA - KREFT (MQOLS-CA)

Nedenfor følger noen spørsmål om din sykdom og din livskvalitet. Vær vennlig å sette ett kryss i den ruten du synes passer best for å beskrive din situasjon.

1. Hvordan er din nåværende helsetilstand?

Ekstremt dårlig helse	0	1	2	3	4	5	6	7	8	9	10	Svært god helse
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

2. Hvor lett eller vanskelig er det for deg å tilpasse deg din sykdom og behandling?

Tilpasningen er ikke lett i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Tilpasningen er veldig lett
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

3. Hvor stor glede har du av livet?

Ingen glede	0	1	2	3	4	5	6	7	8	9	10	Mye glede
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

4. Føler du økonomisk trygghet?

Ingen økonomisk trygghet i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Veldig stor økonomisk trygghet
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

5. Hvis du har smerter, hvor plagsomt er det?

Ikke plagsomt i det hele tatt, eller ingen smerter	0	1	2	3	4	5	6	7	8	9	10	Svært plagsomt
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

6. Hvor nyttig føler du deg?

Ikke nyttig i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Veldig nyttig
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

7. Hvor lykkelig føler du deg?

Føler meg ikke lykkelig i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Svært lykkelig
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

8. Hvor tilfredsstillende er livet ditt?

Ikke tilfredsstillende	0	1	2	3	4	5	6	7	8	9	10	Svært tilfredsstillende
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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9. Får du nok kjærlighet fra familie og venner?

Ikke nok eller for mye kjærlighet	0	1	2	3	4	5	6	7	8	9	10	Akkurat passe med kjærlighet
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

10. Påvirker din sykdom eller behandling dine personlige relasjoner?

Påvirker ikke mine personlige relasjoner i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Meget stor påvirkning på mine personlige relasjoner
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

11. Er du bekymret (redd eller engstelig) for utfallet av sykdommen din?

Aldri bekymret	0	1	2	3	4	5	6	7	8	9	10	Bekymret hele tiden
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

12. I hvor stor grad er du i stand til å gjøre ting du liker å gjøre, som f.eks, å se på TV, lese, gjøre hagearbeid, høre på musikk, gå turer, spille tennis, spille kort, osv.?

Absolutt ikke i stand til å gjøre ting jeg liker å gjøre	0	1	2	3	4	5	6	7	8	9	10	I full stand til å gjøre ting jeg liker å gjøre
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

13. Hvordan er din nåværende konsentrasjonsevne?

Veldig dårlig konsentrasjons- evne	0	1	2	3	4	5	6	7	8	9	10	Utmerket konsentrasjons- evne
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

14. Hvor mye krefter har du?

Ingen krefter i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Mye krefter
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

15. Blir du fort sliten?

Jeg blir ikke fort sliten	0	1	2	3	4	5	6	7	8	9	10	Jeg blir svært fort sliten
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

16. Får du dekket ditt behov for søvn?

Jeg får ikke nok søvn	0	1	2	3	4	5	6	7	8	9	10	Jeg får dekket mitt behov for søvn
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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17. Hvor god er din livskvalitet?

	0	1	2	3	4	5	6	7	8	9	10	
Svært dårlig livskvalitet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Svært god livskvalitet

18. Klarer du å ivareta dine personlige behov (kle på deg, gre håret, gå på toalettet, spise, dusje, bade)?

	0	1	2	3	4	5	6	7	8	9	10	
Jeg kan ikke gjøre noenting selv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Jeg er fullstendig selvhjulp

19. Hvor mye smerter har du?

	0	1	2	3	4	5	6	7	8	9	10	
Ikke smerter i det hele tatt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Svært mye smerter

20. Hvordan er appetitten din?

	0	1	2	3	4	5	6	7	8	9	10	
Ingen appetitt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Utmerket appetitt

21. Hvordan er tarmfunksjonen din?

	0	1	2	3	4	5	6	7	8	9	10	
Det har aldri fungert så dårlig før (enten for mye diaré, eller forstoppelse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Veldig bra tarmfunksjon (regelmessig, ingen diaré eller forstoppelse)

22. Spiser du nok i forhold til ditt behov?

	0	1	2	3	4	5	6	7	8	9	10	
Spiser ikke riktig mengde (for mye eller for lite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Spiser passe mye

23. Er du bekymret for vekten din?

	0	1	2	3	4	5	6	7	8	9	10	
Ikke bekymret for vekten i det hele tatt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Veldig bekymret

24. Er du plaget av kvalme?

	0	1	2	3	4	5	6	7	8	9	10	
Aldri kvalm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Konstant kvalm



Draft

Reg. nr.:

25. Kaster du opp?

Kaster aldri opp	0	1	2	3	4	5	6	7	8	9	10	Kaster opp hele tiden
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

26. Smaker maten annerledes?

Maten smaker som vanlig	0	1	2	3	4	5	6	7	8	9	10	Maten smaker veldig annerledes
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

27. Klarer du å komme deg rundt i den grad du ønsker (gå rundt i rommet, eller hjemmet ditt, komme deg ut, handle, kjøre bil eller ta offentlig transport, osv.)?

Fullstendig bundet til sengen	0	1	2	3	4	5	6	7	8	9	10	Kommer meg rundt på egenhånd
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

28. Hvor fornøyd er du med utseendet ditt?

Meget misfornøyd med mitt utseende	0	1	2	3	4	5	6	7	8	9	10	Meget fornøyd med mitt utseende
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

29. Er du bekymret for noe du ikke har fullført (privat eller på jobb)?

Ikke bekymret i det hele tatt	0	1	2	3	4	5	6	7	8	9	10	Veldig bekymret
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

30. Føler du at du ivaretar ditt ansvar overfor andre (familie, nærmiljøet, kirke, el.)?

Ivaretar ikke dette ansvaret	0	1	2	3	4	5	6	7	8	9	10	Ivaretar dette ansvaret godt
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

31. Har livet mening for deg?

Livet har ingen mening	0	1	2	3	4	5	6	7	8	9	10	Livet er svært meningsfylt
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

32. Får du tilstrekkelig emosjonell støtte fra familie og venner?

Ikke nok eller for mye emosjonell støtte	0	1	2	3	4	5	6	7	8	9	10	Riktig mengde emosjonell støtte
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

33. Føler du at du bidrar til å gjøre andre glad (familie og venner)?

Jeg bidrar ikke til å gjøre andre glad	0	1	2	3	4	5	6	7	8	9	10	Jeg bidrar til å gjøre andre veldig glad
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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RIKSHOSPITALET

Vennligst legg ferdig utfylt spørreskjema i svarkonvolutten. Porto er betalt.

Tusen takk for hjelpen!

Senter for pasientmedvirkning og sykepleieforskning

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